**Special Rapporteur on the rights of persons with disabilities pursuant to Human Rights Council resolution 26/20**

RESPONSE: SAFMH

1. **Please provide information in relation to the existence, in your country or context of work, of legislation and policies concerning mainstream and/or specific social protection programmes with regard to persons with disabilities, including:**

* **Institutional framework in charge of its implementation;**
* **Legislative, administrative, judiciary and/or other measures aiming to ensure access of persons with disabilities to mainstream social protection programmes (e.g., poverty reduction, social insurance, health care, public work, housing);**
* **Creation of disability-specific programmes (such as disability pensions, mobility grants or others);**
* **Fiscal adjustments or other similar measures.**
  1. In South Africa, the draft White Paper on the Mainstreaming of the Right of Persons with Disabilities to Equality and Dignity, hereafter referred to as The National Disability Rights Policy (NDRP), once approved by Cabinet, will update the White Paper on an Integrated National Disability Strategy (INDS), and will integrate the obligations contained in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) as well as the provisions of the Continental Plan of Action for the African Decade of Persons with Disabilities with South African legislation and policy frameworks and the National Development Plan 2030.

*\*See attached comment document submitted by the South African Federation for Mental Health (SAFMH), which contains several aspects of all the questions raised in this questionnaire.*

1. **Please provide information on how persons with disabilities are consulted and actively involved in the design, implementation and monitoring of social protection programmes in your country or context of work.**
   1. The SA Federation for Mental Health (SAFMH) is a registered national, not for profit, non-governmental organisation (000-238 NPO), constituted by 17 Mental Health Societies and 107 Member Organisations, all actively involved in the field of intellectual and psychosocial disability and mental wellbeing. The organisation was established in 1920 with the aim to coordinate, monitor and promote services for persons with intellectual and psychosocial disability, as well as promote good mental health and wellbeing amongst the South African public.

The mission of the organisation is to actively work with the community to achieve the highest possible level of mental health for all by:

* Enabling people to participate in identifying community mental health needs and responding appropriately;
* Developing equal, caring services for people having difficulty coping with everyday life, and those with intellectual and / or psychosocial disability;
* Creating public awareness of mental health issues;
* Striving for the recognition and protection of the rights of individuals with intellectual and / or psychosocial disability;
* Aspiring to contribute to a just and fair society

The organisation’s key areas of work are:

* Capacity Building – as a national organisation, it is the organisation’s role to capacitate its constituencies with skills, thereby ensuring that services they deliver are of a high standard. This also involves building the capacity of mental health care users and other partner organisations through training initiatives
* Social Integration – this is focused on the integration of persons with intellectual and / or psychosocial disability into society. Due to myths, stigmatisation, poverty and the lack of support systems, society in general (including the labor market) is sometimes hesitant in accepting persons with intellectual or psychosocial disability
* Human Rights – the organisation monitors services rendered to persons with intellectual and / or psychosocial disability to try and ensure their full integration into society, along with supporting the upholding of their constitutional rights, as enshrined in the Mental Health Care Act of 2002 and the UN Convention on the Rights of Persons with Disabilities
* Mental Health Awareness – the organisation raises awareness about services rendered by SAFMH and advocates for the rights of persons with intellectual and psychosocial disability. The overall purpose of creating awareness about mental disabilities is to dispel myths and stigma attached to these disabilities, and ultimately to eradicate discrimination. The promotion of mental wellbeing is equally important and focuses on preventative measures through the promotion of healthy lifestyles. As part of this, SAFMH supports World Mental Health Day on the 10th of October annually, as well as other commemorative events, including Intellectual Disability Awareness during March, Psychosocial Disability Awareness during July and mental wellbeing and health promotion and awareness during October.
* Research – is conducted on an ongoing basis on mental health-related issues, both nationally and internationally, to enable SAFMH to effectively function as a mental health information hub and resource centre, along with informing all other areas of focus
* Corporate wellbeing – the organisation offers mental health information and awareness sessions to the corporate sector that are customized to suit their needs. Corporate wellness sessions are also a source of income for SAFMH
* Advocacy – is a key focus of SAFMH’s work and cuts across most of the other priority areas. It is a vital part of the organisation’s work and an important outcome of most of the work it engages in

The organisation’s key areas of focus are extremely integrated and cross-cutting and all form part of the overall aims and objectives of the organisation.

* 1. SAFMH is linked to the Disability Unit within the Department of Social Development (DSD) and receives notices on developments within the sector and calls for reviews of policies and legislation, and we act accordingly. Representatives of SAFMH attend the Disability Machinery meetings hosted by DSD and other relevant meetings. As from 2014, the Disability Rights Parliament hosted its inaugural session in parliament where SAFMH was represented.
  2. SAFMH is also linked to the Department of Health as psychosocial and intellectual disabilities fall under the Mental Health Care Act 17 0f 2002 (http://www.justice.gov.za/legislation/acts/2002-017\_mentalhealthcare.pdf). SAFMH recently submitted its comments to the MHCA Regulations that were up for review. *\*Please find attached SAFMH comments to the MHCA Regulations.*

1. **Please provide information in relation to difficulties and good practices on the design, implementation and monitoring of mainstream and/or specific social protection programmes with regard to persons with disabilities, including:**

* **Conditions of accessibility and the provision of reasonable accommodation;**
* **Consideration of the specific needs of persons with disabilities within the services and/or benefits of existing programmes;**
* **Difficulties experienced by persons with disabilities and their families in fulfilling requirements and/or conditions for accessing social protection programmes;**
* **Consideration to age, gender and race or ethnic-based differences and possible barriers;**
* **Conflicts between the requirements and/or benefits of existing programmes, and the exercise by persons with disabilities of rights such as the enjoyment of legal capacity, living independently and being included in the community, or work;**
* **Allocation of grants to personal budgets;**
* **Disability-sensitive training and awareness-raising for civil servants and/or external partners;**
* **Existence of complaint or appeal mechanisms.**
  1. SAFMH has developed an intensive 4-year plan for its South African Mental Health Advocacy Movement (SAMHAM) with the main aims of establishing mental health care user advocacy groups in all 9 provinces within South Africa and empowering persons with psychosocial and intellectual disabilities within these structures. *\*Please see attached information document on SAMHAM.*
  2. SAFMH developed a reporting system for human rights violations called the Mental Health Watch. *\*Please see attached information document on the Mental Health Watch.*
  3. The SAFMH comment submission on the draft White Paper on the Mainstreaming of the Right of Persons with Disabilities to Equality and Dignity *(attached)* covers much of the questions raised above.
  4. SAFMH in partnership with The Ubuntu Centre and other organisations in the field of mental health, as well as the Legal Resource Centre, is currently addressing a matter related to the *Right to Vote* as it currently excludes persons with psychosocial and intellectual disabilities. So far we had a promising meeting recently with the Independent Electoral Commission (IEC) to put in motion the change in legislation. *\*Please see attached communication document to the IEC.*
  5. SAFMH, along with the QuadPara Association of South Africa (QASA) and the Legal Resource Centre is also in the process of addressing unfair discrimination related to the Civil Aviation Authority Regulations for aircraft passengers. The current South African Civil Aviation Association (SACAA) Civil Aviation Regulations (2011): Carriage of Passengers with Disability (<http://www.caa.co.za/New%20Notices/CIVIL_AVIATION_REGULATIONS-2011.pdf>) contain discriminatory requirements for persons with disabilities. As a result of both the wording and interpretation of the above Regulations, a number of airlines in South Africa have significantly limited disabled persons’ ability to travel by air. This is because the Regulation mandates all passengers who are physically or mentally disabled to be accompanied by an abled bodied assistant in order to fly. This is an expense that a disabled passenger seeking to travel is responsible for. The Regulation is applied indiscriminately to all disabled persons without considering the nature of their disability and the limitations of each individual person, and the Regulation fails to take into consideration the personal circumstances of each disabled passenger seeking to travel by air.

1. **Please provide any information or data available in your country or context of work, disaggregated by impairment, sex, age or ethnic origin if possible, in relation to:**

* **Coverage of social protection programmes by persons with disabilities;**
* **Rates of poverty among persons with disabilities;**
* **Additional costs or expenses related to disability.**
  1. A serious problem currently experienced in South Africa is access to social security (disability grant).

The South African Federation for Mental Health (SAFMH) and the South African Mental Health Advocacy Movement (SAMHAM) have been receiving numerous reports of persons with psychosocial disability whose disability is of such a nature that they are unable to obtain or maintain employment, and whose disability grant applications have been declined and whose appeals have failed. It has been reported that responses from SA Social Security Agency (SASSA) have often been unreasonable and even discriminatory.

Whilst we recognise that many of the reports we receive are based on anecdotal evidence, we have received many such reports over the past few years and are thus convinced that there definitely are problems in terms of the treatment of persons with psychosocial disabilities.

From the outset, it is important to understand the need for Disability Grants within the world of psychosocial disability. Psychosocial disability, including conditions such as schizophrenia and bipolar disorder, may well be managed by medication, leading to the person being stable; however, a major contributing factor to relapse or the reoccurrence of symptoms is stress. The person may be stabilised and function well within a protective environment such as a residential care facility, but the moment such a person is placed in a highly structured, formal working environment, they become prone to relapsing. Increasingly so when stigma and discrimination creates an environment in the workplace where no support or understanding of the employee with a psychosocial disability exists and where their needs are not accommodated (such as making the effort to reduce stress levels as far as possible).

Within this context, it is important to note that the average unemployment rate among the general South African population is 25%. It is estimated that the unemployment rate amongst persons with psychosocial disability is however between 70-90%. Realistically, a person with a psychosocial disability who is employable has an extremely slim chance of obtaining employment – in particular if they disclose their disability.

It is important to acknowledge that the impairments caused by disability are not the only factors that result in disabling affects which interfere with daily functioning in society. Stigma and discrimination often has an equal or even greater impact, especially in the case of persons with psychosocial disability, who end up having to face the consequences of both the psychosocial disability itself and the harrowing effects of stigma and discrimination. Stigma and discrimination have been challenges in the mental health field for decades despite continuous efforts to try and change people’s attitudes toward persons with psychosocial disabilities.

Large numbers of persons with psychosocial disabilities, many of whom live in residential care facilities, have been abandoned and neglected by their families and thus receive no or very little financial support. These individuals rely heavily on their disability grants to pay their fees at residential facilities which provide a structured and protective care environment.

SASSA is guided by the eligibility criteria outlined in Section 9(b) of the Social Assistance Act, 2004 (Act No.13 of 2004), which states that a person is eligible for a disability grant if he or she is *“owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance”*.

Based on the reports we have been receiving, it appears that the medical assessors at SASSA, using the prescribed guidelines, mainly aim to determine current levels of functioning, and whether the person’s psychosocial disability places limitations on normal daily activities. In this regard, it is extremely important that SASSA’s medical assessors recognise the fact that persons with psychosocial disabilities, who are at the time stabilised on treatment and who live in protective environments, may not necessarily be employable. The stresses of employment often threaten their stability, which lead to many people experiencing relapses. Such relapses bring about a significant deterioration in functioning, which becomes worse with each relapse and which is irreversible.

* 1. Another concern is the lack of access to essential medications – where community based clinics often experience ‘stockouts’ of several medications to treat psychosocial disability and limit the impact of disability in persons with a diagnosis. SAFMH partnered with the “Stop Stockouts” campaign (<http://stockouts.org/>) that aims to resolve medication shortages timeously through the relevant channels within the Department of Health.

At the same time, South Africa’s patent laws allow for “evergreening” and thus often prevent cheaper generic medications from entering the market, ultimately resulting in medications being unaffordable and inaccessible. SAFMH partnered with the “Fix the Patent Laws” campaign (<http://www.fixthepatentlaws.org/>) that is currently addressing this issue and the campaign submitted recommendations to Government.

1. **Please provide information in relation to the eligibility criteria used, in your country or context of work, for accessing mainstream and/or specific social protection programmes with regard to persons with disabilities, including:**

* **Definition of disability and disability assessments used for eligibility determination;**
* **Consistency of the eligibility criteria among different social protection programmes;**
* **Use of income and/or poverty thresholds;**
* **Consideration of disability-related extra costs in means-tested thresholds.**
  1. Refer to point 4.1. where persons with psychosocial disabilities (who should fit the criteria) are being denied access to a social disability grant as it seems to be not recognised as a disability.
  2. In other sectors, e.g. open labour market, psychosocial disability is also often not recognised as a disability and thus denied employment equity.
  3. Many extra costs involved with psychosocial disability are often not acknowledged, e.g. regular dental treatment as medication side-effects cause deterioration of teeth; vitamin supplements as medication side-effects impact on the immune system and other organs; mobile phone that alert the person of treatment and appointment times; and a new form of assistance not yet available in South Africa, is a treatment therapy dog.
  4. The link to this article describes all the relevant assistive technologies applicable to persons with intellectual disabilities:

<http://www.tamcec.org/wp-content/uploads/2013/05/AT-Supports-IDD.pdf>.

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