Transforming Communities for Inclusion

The Addis Declaration

We, persons with psychosocial disabilities from 5 countries in East Africa region (Ethiopia, Kenya, Malawi, Rwanda, Uganda), met in Addis Ababa, on July 26, 2022, at the East Africa Subregional Convening, organized by Transforming Communities for Inclusion – Global in partnership with CIC-Kenya¹, TRIUMPH², RDDF³ and UNSAI⁴, and developed the ‘Addis Declaration’, through a consultative process, over 2 days.

In September 2023, TUSPO⁵, an organization of persons with psychosocial disabilities from Tanzania also adopted the Addis Declaration.

Under the rubric of ‘persons with psychosocial disabilities’,

We include all persons who self-identify as persons with psychosocial disabilities, users and survivors of psychiatry, ‘mad’ persons, autistic persons, persons who face discrimination and exclusion based on our intersectional and neurodiverse identities, and persons from Commonwealth nations of Africa who are still accused by law, of being of ‘unsound mind’ or a ‘lunatic’.

Hereby confirming,

- The systematic and pervasive violence and the violation of all human rights of persons with psychosocial disabilities, including all forms of discrimination, exclusion, violence, inhuman, cruel, degrading and torturous treatments taking place in East African nations, in cities, urban, rural and remote areas; in institutions and in communities; in schools, universities, work places, health care centers and within social services;

- The failure of the past, present and new legal and policy responses framed by the medical model, including new mental health laws, amendments of old laws, which are increasing the presence and number of prison like institutions in the East African subregion; restricting

¹ Championing Inclusive Communities in Kenya (CIC-K)
² Triumph Uganda Mental Health Support and Recovery Program
³ Rights for Disability Development Foundation
⁴ Uganda National Self-Advocacy Initiative
⁵ Tanzania Users and Survivors of Psychiatric Organization
freedoms, choices and opportunities for living independently in communities; increasing the gatekeeping over lives of persons with psychosocial disabilities, especially women and girls with disabilities, by the mental health system by assessing, conditioning, controlling and restricting our exercise of our rights; resulting in overmedication, forced institutionalization, electroshock, forced sterilization, abortions, sexual abuse, hysterectomies and other inhuman, degrading, violent and torturous treatments; denying our legal capacity, including the right to decision making at all levels; often ignoring resources for inclusion within families, communities, cultures, belief systems that may increase our choices and chances of full inclusion;

- Those legal and policy responses often centered on an archaic medical model based on coercive mental health care, do not comply with international human rights standards and, frameworks provided by various human rights mechanisms and international Conventions and treatises, most importantly, the UN Convention on the Rights of Persons with Disabilities [CRPD]⁶; further elaborated in General Comment 1⁷ and General Comment 5⁸; the more recent Guidelines on De-institutionalization (including during emergencies)⁹; further, calling medical, psychiatric and social care as ‘psychological torture’¹⁰, described in detailed reports of the Special Rapporteur (Highest standard of health and wellbeing) in 2017¹¹ and 2020¹² who described the ‘Biomedical dominance’, ‘Power Imbalance’ and ‘Global burden of Barriers’ facing all persons with psychosocial disabilities; leading to extreme human rights violations within a care system and called for a shift from ‘mental health to human rights’;

- Our exclusion from all arenas of Sustainable Development, including work and employment, economic inclusion, social protection, housing, education, family life, participation in cultural, social life, leisure and

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⁷ CRPD/C/GC/1
⁸ CRPD/C/GC/5
⁹ CRPD/C/5
¹⁰ A/HRC/43/49
¹¹ A/HRC/35/21
¹² A/HRC/44/48
sports, political participation, and violations of our rights in health care, habilitation and rehabilitation, access to affordable and accessible social services; having no access to citizenship or domiciliary status, or disability status; the barriers to living life independently in the communities without interruption, access to trusted support systems and social networks, thereby limiting per force our social capital;

**Gravely concerned** about the pervasive trend of globalizing mental health and allied developments which solely focus on psychiatrizing human responses to social, economic, political distress, disadvantage and discrimination; the colonial baggage in policy and the colonial mentality within the mental health care system, which are exporting ‘solutions’ from the global north and embedding them within the global south realities; often violating culturally grounded belief systems and practices of healing, unity of families, neighbourhoods and community support, by interrupting community life with institutionalization;

**Alarmed** by the extent to which even the most progressive mental health care environment still controls and denies our rights to education, work, having a family, financial independence, independent living arrangements, housing, access to social protection, food, basic needs and an adequate standard of living; rights to vote, life and liberty, equal recognition before the law, among all other rights guaranteed by the human rights framework; often applying guardianship upon us against our will and preference;

**Gravely concerned** that women and girls, and women and girls with psychosocial disabilities often remain invisible and marginalized; the exclusion of women with psychosocial disabilities from important and relevant decision making spaces has continued despite a multitude of human rights instruments advocating for our rightful inclusion in all development agendas and processes; that violence and abuse (physical, sexual, emotional) against women in public and private spaces still exists; that they face atrocious human rights violations while incarcerated in institutions; are unable to exercise our rights to bodily autonomy, control our own sexual and reproductive rights, subjected to involuntary sterilization, forced contraception and abortions; unable to decide for our own family and children;
Concerned about the social, legal and other barriers to building a strong, social and human rights movement of persons with psychosocial disabilities in the subregion; the co-optation of our voices by the psychiatric and mental health momentum prevailing in Africa; legal barriers to forming associations of persons with psychosocial disabilities; and our under representation in other movements such as women’s movement, disability movement and human rights movements;

Among the issues of sustained discrimination, and exclusion of persons with psychosocial disabilities, we highlight as grave:

- The barriers to choosing our identity position as persons with psychosocial disabilities;
- Co-optation by the mental health momentum and presence of INGOs multiplying mental health programs, with our core problems of human rights violations, coercion and medicalization;
- Dismissal of traditional beliefs, cultural competence, community support systems and local indigenous practices of succor, support and healing;
- Lack of adequate investment into community based services, social protection, work and employment opportunities;
- Our complete invisibility in all data collection systems and records;
- Diversion of all funding towards institutional infrastructure and very little for fostering community inclusion practices, particularly housing, social protection and skill development;

That, such concerns are not being a sporadic occurrence but confirmed as frequent occurrences, in all parts of East Africa; deeply embedded within legal, normative, and social structures; being reinforced by colonial, historical traditions set within national laws and policies;

That, such violations in law and practice cannot be addressed by marginally improving mental health systems that perpetuate the denial of human rights in the name of ‘our best interest’, but by adopting the full shift of paradigm of the CRPD towards inclusion in accordance with our choice, will and preference;

13 International Non-Government Organizations (INGOs)
Encouraged by the absence of mental health laws and legislations in some countries in Africa and Asia, reflecting and confirming that a history of non-colonization or limited colonization has resulted in the State adopting general health laws or disability legislation instead of stand-alone mental health legislations; thus, ensuring the inclusion of persons with psychosocial disabilities within policies and legislation for the inclusion of all persons with disabilities; confirming the absolute relevance of the paradigm shift towards the social model, towards ‘inclusion’ and away from the medical model;

Recalling the obligation of East African countries that have ratified the CRPD to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for our inherent dignity, autonomy and independent decision making on equal basis with others; and commitments made under the SDGs;14; And the commitment of all Member States of the African Union to various human rights instruments adopted with provisions for the rights of persons with disabilities, including to the African (Banjul) Charter on Human and Peoples’ Rights (1981)15, the Protocol to the African Charter on Human and People’s Rights on the Rights of Persons with Disabilities in Africa (2018)16; Further recalling, commitments of East African nations to the African Charter On The Rights And Welfare Of The Child (1990)17, Agenda 206318, Maputo Protocol: Protocol to the African Charter on the Rights of Women in Africa (2003)19, African Youth Charter (2006)20, African Charter on Democracy,

14 Sustainable Development Goals (SDGs)
Elections and Governance 2007\(^{21}\) and African Union Convention for the protection and assistance of internally displaced persons in Africa 2009\(^{22}\), which make provisions for ensuring the rights of persons with disabilities;

Recalling, the Commitment of all Member States of the African Union to Protocol to the African Charter on Human and People’s Rights on the Rights of Persons with Disabilities in Africa (2018)\(^{23}\);

Welcoming

- The concluding observations and recommendations of the UN CRPD committee to East African countries to date\(^{24}\), as well as the General Comments on Equal Recognition Before the Law (Art 12)\(^{25}\); Women with Disabilities (Art 6)\(^{26}\); Living independently and being included in the community (Art19)\(^{27}\); Non-discrimination and Equality (Art 5)\(^{28}\); among others,
- The range of reports of the UN Special Rapporteur on the Rights of Persons with Disabilities to the UN Human rights Council on social protection, inclusive policy, legal capacity and participation and rights-based support for persons with disabilities,
- The report from the Special Rapporteur on the Right to highest standards of physical and mental health to the Human Rights Council on Mental Health, statement on the ‘corruption’ in the mental health systems around the world\(^{29}\),
- The 2017 Human Rights Council Resolution on Mental Health and Human Rights\(^{30}\), including call to address the underlying social, economic and environmental determinants of health; to abandon all


\(^{24}\) CRPD/C/KEN/CO/1, CRPD/C/UGA/CO/1, CRPD/C/RWA/CO/1, CRPD/C/ETH/CO/1

\(^{25}\) CRPD/C/GC/1

\(^{26}\) CRPD/C/GC/3

\(^{27}\) CRPD/C/GC/5

\(^{28}\) CRPD/C/GC/6

\(^{29}\) A/HRC/41/34

\(^{30}\) A/HRC/36/L.25
practices that fail to respect the rights, will and preferences of all persons; de-institutionalization; to prevent over medicalisation and to promote and respect the enjoyment of the rights to liberty and security of person and to live independently and be included in the community.

In full realization of all human rights as enshrined in the CRPD, and especially the human right to live independently and be fully included in communities (Article 19, General Comment 5), we want (1) to be able to decide our place of residence and who we want to live with (2) have access to a range of in home, residential and/or community support services nearby our places of residence (3) be included in all services available on equal basis with others and (4) all services should be responsive to our general and specific needs.

Call for actions

In tune with the Bali Declaration of Transforming Communities for Inclusion\textsuperscript{31}, and inclusive of all proactive actions describe therein, we, persons with psychosocial disabilities from East African nations, call for additional actions -

That recognize the involvement of a paradigm shift in creating a suitable policy environment for the inclusion of persons with psychosocial disabilities, involving validation of our identity as persons with psychosocial disabilities; reframing from a medical model to social model; ‘mental disorder’ or ‘mental health condition’ to psychosocial disability; from ‘public health’ to inclusion in development; ‘institutionalization’ to de-institutionalization; ‘treatment’ to support systems; ‘patients’ to ‘citizens’; involving the repeal of standalone mental health legislations to inclusion in disability legislations evoking the guidance of the CRPD to bridge such reframing;

That will place the inclusion of persons with psychosocial disabilities as the purpose, process and outcome of all social, legislative, policy, program, service actions, across all sectors, involving all actors including, but not limited to health care and within all Development agendas, plans, programs and partnerships for social change;

\textsuperscript{31} Bali Declaration (2018) \url{https://www.tci-global.org/bali-declaration/}
That will avoid or will go beyond harm reduction approaches for example, to revive and reform care systems towards ‘humane’ mental health care; attempts to create a ‘CRPD compliant mental health law’; paraphrasing systemic flaws of an archaic colonial system into ‘institutional staffing and behavioural issues’; promotion of ‘Quality rights’ by staff education while not dismantling the institutional legal and physical infrastructures;

That our right to full and equal recognition before the law be immediately recognized by all countries in our sub region; that all national laws be harmonized with the CRPD so that no one with a psychosocial disability shall be denied a civil, social, political, economic or cultural right on the basis of ‘incapacity’, ‘lunacy’, ‘mental illness’, ‘mental health condition’ or ‘unsoundness of mind’; the legal frameworks including the Constitution be reformed by repealing and abolishing all discriminatory legislations and provisions; that all future technical, ethical and other guidelines, policies, legislations, and any other efforts be developed involving our full and effective participation and inclusion; that all such actions be mindful of the paradigm shift from mental health to inclusion and that all such processes be led by persons with psychosocial disabilities and our representative organizations;

That accessible, affordable and good quality program measures be available for deinstitutionalization; including community-based support systems and services, peer support groups, neighbourhood sensitisation schemes, stakeholder awareness and support, formal and informal networks of support, crisis support as needed; stress relief spaces in the community like peer respite centers, listening hubs, safe spaces for active listening, gardens, sports facilities, community centers;

That community based specific psychosocial and trauma informed services are available in the community itself, closer to our homes; that such services do not amount to ‘occupational therapy’, outdoor or garden labour or sheltered workshops; that support persons are trained to dialogue and negotiate safety issues on the basis of the will and preference of persons with psychosocial disabilities, to prevent institutionalization and / or continued violence against the persons with psychosocial disabilities in the community;
That persons with psychosocial disabilities face multiple and coexisting forms of discrimination or intersectional discrimination; that the State and stakeholders should recognise these layers of our identities and acknowledge the discrimination meted out to youth, women, persons of colour, indigenous populations, children, intersectional, gender diverse and neurodiverse communities, elderly population and persons with autism;

That the right to adequate standards of living, right to housing, right to inclusive social protection be realized for the inclusion of persons with disabilities in all social security programs; cash transfers to be provided for covering disability related costs for persons with psychosocial disabilities; that there be spaces in social protection schemes to advocate for the needs and benefits of persons with psychosocial disabilities; these social security schemes should be meaningfully and effectively implemented to prevent institutionalization, promote and support living in communities; that persons leaving institutions do not face situations of poverty, homelessness or unemployment; such schemes be designed to ensure the dignity, respect, autonomy and independent living of all persons with psychosocial disabilities;

That the right to work and employment must be realized with the inclusion of persons with psychosocial disabilities in all job markets, employment exchanges, job placements and support for livelihood opportunities; provision of reasonable accommodation; measures such as support, flexible hours, quiet spaces in the offices, disability benefits at work, on equal basis with others; opportunities for skill development, job promotions, availability of spaces to advocate with employers on work and employment for persons with psychosocial disabilities; provision of job protection for persons undergoing a crisis situation;

That the right to education be realized within all education systems supported by reforms towards lifelong learning; reasonable accommodation; access to flexible curriculum adapted to the learner’s needs, alternative and augmentative means of communication such as nonverbal / activity based / arts-based learning; opportunities to complete education in preferred stream of subjects;
That the right to political participation is ensured in all countries of the subregion, especially the right to vote, stand in elections, hold public office, participate in rallies, form associations of persons with psychosocial disabilities, etc. on an equal basis with others; that constitutional prohibitions on voting, right to representation and full political participation be immediately removed;

That all data collection instruments must be inclusive of persons with psychosocial disabilities; that new tools and instruments should be developed to capture all data related to persons with psychosocial disabilities particularly in country census; the State should be meticulous in ensuring data related to persons with psychosocial disabilities is captured in all disability assessment work, all programs and schemes of the government, from a CRPD compliant perspective; that all data captured should be disability disaggregated;

That protection and safety of persons with psychosocial disabilities must be ensured in situations of risk and humanitarian emergencies (such as armed conflict, occurrence of natural disasters); the Disaster Risk Reduction plans, disaster management plans, long term recovery and reconstruction efforts should be inclusive of needs of persons with psychosocial disabilities; that institutions shall not be built under the guise of ‘building back better’; that de-institutionalization efforts be immediately set in motion in such situations, as per the Guidelines on De institutionalization including during emergencies; that persons with psychosocial disabilities and our representative organizations should be meaningfully engaged and included in the preparation and execution of all such plans;

That the right to health care be realized, including access to all general health services, should be more affordable, accessible and available to all persons with psychosocial disabilities; that informed consent and other biomedical ethical practices be strictly followed by medical and health care professionals; that persons with psychosocial disabilities be offered the full range of Sexual Health and Reproductive Health services; and holistic and various kinds of culturally sensitive healing and well-being methods are also available in the health care system and offered; that inhuman, degrading and cruel practices
such as forced sterilization and hysterectomies be prohibited in national health laws;

That measures be strictly put in place to ensure freedom from violence, abuse and exploitation, and the use of inhuman, degrading and torturous treatments such as forced sterilization, FGM\textsuperscript{32}, hysterectomies; ensuring full and effective participation of women and girls with disabilities in all decision making processes; that States in the sub region should ensure long term planning and efficient allocation of resources towards this end; that legal reforms should be enforced to repeal any discriminatory legislations that rob the right to personhood for women and girls with psychosocial disabilities.

We aspire,

✓ To the extent that all such progressive actions for our inclusion are in our interest, to contribute to those actions through co-operations on trainings, capacity building, guidance on inclusion, research and any actions thereof, towards re-directing the legislative and policy environment towards inclusion;

✓ To work with organisations whose goals are aligned with ours, and which respect the principle of leadership and full and effective participation of persons with psychosocial disabilities and our expertise on all matters that concern our lives and our rights, in the drive for social change;

✓ To have a meaningful place in our societies, be it through paid work, social justice work, creative work, informal care and support work, or so on. We believe that an environment that facilitates the full development of our human potential in all its diversity will also further the social, economic, cultural and political advancement of our societies.

\textsuperscript{32} Female Genital Mutilation (FGM)