



# General Assembly

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### Third Committee

Agenda item 28

#### Social development

**Brazil, Central African Republic, Equatorial Guinea, France, Italy, Portugal, Qatar and Spain: draft resolution**

### **Addressing the challenges of persons living with a rare disease and their families**

*The General Assembly,*

*Recalling* the Universal Declaration of Human Rights,<sup>1</sup> the International Covenant on Economic, Social and Cultural Rights,<sup>2</sup> the Convention on the Elimination of All Forms of Discrimination against Women,<sup>3</sup> the Convention on the Rights of the Child,<sup>4</sup> the Convention on the Rights of Persons with Disabilities<sup>5</sup> and the Constitution of the World Health Organization,<sup>6</sup>

*Reaffirming* its resolution [70/1](#) of 25 September 2015, entitled “Transforming our world: the 2030 Agenda for Sustainable Development”, in which it adopted a wide, far-reaching, and people-centred set of universal and transformative Sustainable Development Goals and targets, and its commitment to working tirelessly for the full implementation of the Agenda by 2030, ensuring that no one is left behind,

*Taking note* of the reports of the first and second high-level meetings of the NGO Committee for Rare Diseases, held at United Nations Headquarters in New York on 11 November 2016 and 21 February 2019,

*Recognizing* the need to promote and protect the human rights of all persons, including the estimated 300 million persons living with a rare disease worldwide, many of whom are children, by ensuring equal opportunities to achieve their optimal developmental potential and to participate in society,

*Reaffirming* the right of every human being, without distinction of any kind, to the enjoyment of the highest attainable standard of physical and mental health and to

<sup>1</sup> Resolution [217 A \(III\)](#).

<sup>2</sup> See resolution [2200 A \(XXI\)](#), annex.

<sup>3</sup> United Nations, *Treaty Series*, vol. 1249, No. 20378.

<sup>4</sup> *Ibid.*, vol. 1577, No. 27531.

<sup>5</sup> *Ibid.*, vol. 2515, No. 44910.

<sup>6</sup> *Ibid.*, vol. 14, No. 221.



a standard of living adequate for the health and well-being of oneself and one's family, including adequate food, safe drinking water, clothing and housing, and to the continuous improvement of living conditions, with particular attention to the alarming situation of millions of people for whom access to health-care services and medicines remains a distant goal, in particular those who are vulnerable or in vulnerable situations,

*Reaffirming also* that health is a precondition for and an outcome and indicator of the social, economic and environmental dimensions of sustainable development and the implementation of the 2030 Agenda for Sustainable Development, and acknowledging the reciprocal benefits between the attainment of Sustainable Development Goal 3 and the achievement of all other Goals,

*Recognizing* the fundamental importance of equity, social justice and social protection mechanisms as well as the elimination of the root causes of discrimination and stigma in health-care settings to ensure universal and equitable access to quality health services without financial hardship for all persons living with a rare disease, particularly for those who are vulnerable or in vulnerable situations,

*Recalling* the high-level meeting on universal health coverage, held in New York on 23 September 2019, and reaffirming its political declaration, entitled "Universal health coverage: moving together to build a healthier world",<sup>7</sup> including the commitment therein to strengthen efforts to address rare diseases as part of universal health coverage,

*Noting with concern* the threat to human health, safety and well-being caused by the coronavirus disease (COVID-19) pandemic, which has spread all around the globe, as well as the unprecedented and multifaceted effects of the pandemic, including the disruption of essential health services, and recognizing the disproportionate impact of COVID-19 on the health, social and economic situation of persons living with a rare disease,

*Expressing concern* that persons living with a rare disease and their families are disproportionately affected by stigma, discrimination and social marginalization,

*Recognizing* that a major barrier to improving the inclusion and participation of persons living with a rare disease and their families in society is the lack of knowledge and expertise in the field and a lack of awareness regarding the issue,

*Recognizing also* that persons living with a rare disease and their families constitute a psychologically, socially, culturally and economically vulnerable population throughout their life course, facing specific challenges in several areas, including but not limited to health, education, employment and leisure,

*Acknowledging* the significance of raising awareness and engaging and empowering people and communities in respect of the needs of persons living with a rare disease,

*Reaffirming* that inclusive and equitable quality education and lifelong learning opportunities without discrimination are essential for participation in social and economic life, and that children living with a rare disease face challenges in accessing quality education owing to the inaccessibility of facilities and non-adapted teaching methods,

*Reaffirming also* that access to full and productive employment and decent work is also an important aspect of participation in social and economic life, and that

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<sup>7</sup> Resolution [74/2](#).

persons living with a rare disease and their families face challenges in access to, retention of and return to employment,

*Reaffirming further* the need to achieve gender equality and to empower women and girls, and concerned by the fact that women living with a rare disease face more difficulties in accessing health services and that women undertake a disproportionate share of unpaid care work when a member of the family lives with a rare disease,

*Deeply concerned* that persons living with a rare disease, especially children, often face barriers in accessing water and sanitation facilities that are accessible and appropriate to their needs, which has an impact on their ability to live independently and participate fully in all aspects of life, including education and employment, which is particularly concerning in situations of homelessness, as well as in humanitarian emergencies and crises,

*Underscoring* the need to address the root causes of vulnerability of persons living with a rare disease and their families, and in this regard recognizing that there is a need for policies and programmes to prevent and combat prejudice, to foster inclusion and to create an environment conducive to respect for their rights and dignity,

*Reaffirming* the need to foster innovation, and recognizing the need to support, streamline and prioritize research on rare diseases,

*Expressing concern* at the absence of disaggregated data on the status of persons living with a rare disease, which would help to identify and address the barriers faced in exercising their rights,

*Recognizing* the important role of civil society organizations representing persons living with a rare disease, which gather, produce and disseminate the limited existing information on the challenges of persons living with a rare disease, provide support services to them and advocate for better lives on their behalf, and recognizing also the effective and meaningful participation of persons living with a rare disease in decision-making, through their representative organizations,

*Reaffirming* the need for the participation of persons living with a rare disease in development efforts at the national, regional and international levels, and in this regard stressing the need to strengthen the effectiveness of national, regional and international policy and development programmes related to persons living with a rare disease,

*Expressing appreciation* for the efforts made by Member States, the United Nations system and relevant stakeholders, including the NGO Committee for Rare Diseases, to prevent and address the situation of persons living with a rare disease and their families, but mindful of the need for further action,

1. *Calls upon* Member States to strengthen health systems, notably in terms of primary health care, in order to provide universal access to a wide range of health-care services that are safe, quality, accessible, available and affordable, timely, clinically and financially integrated, people-centred, gender-sensitive and community-based, which will help to empower persons living with a rare disease in addressing their physical and mental health needs, enhance health equity and equality, end discrimination and stigma, eliminate gaps in coverage and create a more inclusive society;

2. *Encourages* Member States to adopt national strategies, action plans and legislation, as appropriate, on the rights of persons living with a rare disease, in conformity with international human rights obligations and commitments;

3. *Also encourages* Member States to address the root causes of discrimination against persons living with a rare disease, including through awareness-raising, the dissemination of accurate information on rare diseases and other measures, as appropriate;

4. *Encourages* Member States and relevant United Nations agencies to collect, compile and disseminate disaggregated data on persons living with a rare disease, where applicable, to identify patterns of discrimination and to assess progress towards the improvement of the status of persons living with a rare disease;

5. *Encourages* Member States to foster the creation of networks of experts and multidisciplinary specialized expert centres for rare diseases and to increase support for research, by strengthening international collaboration and coordination of research efforts and the sharing of data;

6. *Also encourages* Member States to develop, as appropriate, policies and measures to address the social development and inclusion challenges faced by persons living with a rare disease, who may require assistance in order to enjoy equal access to benefits and services, notably in the fields of education, employment and health, and to promote their participation in political, civil, economic, social and cultural life by providing the opportunity to civil society organizations of persons living with a rare disease to contribute towards evidence-based and informed decisions;

7. *Urges* Member States to implement, as appropriate, national measures to ensure that persons living with a rare disease are not left behind, recognizing that persons living with a rare disease are often disproportionately affected by poverty, discrimination and lack of decent work and employment, and to commit to working towards the social integration and physical and mental well-being of persons living with a rare disease;

8. *Urges* Member States, United Nations agencies and other stakeholders, in cooperation with persons living with a rare disease and their families, including through their representative organizations, to design and implement policies and programmes to fulfil the rights of persons living with a rare disease, including through developing, reviewing and strengthening inclusive policies to address the structural and underlying causes of stigma and discrimination faced by them, and to ensure that the implementation of the 2030 Agenda for Sustainable Development<sup>8</sup> is inclusive of and accessible to persons living with a rare disease;

9. *Affirms* that persons living with a rare disease, including children, have the right to inclusive and equitable education and lifelong learning opportunities on the basis of equal opportunity and non-discrimination, and urges Member States to ensure full access to education and lifelong learning opportunities for persons living with a rare disease on an equal basis with others by taking appropriate steps through the provision of information in accessible and alternative communication formats, reasonable accommodation, accessible facilities, adapted teaching methods and other support, as required;

10. *Calls upon* Member States to accelerate efforts towards the achievement of universal health coverage by 2030 to ensure healthy lives and promote well-being for persons living with a rare disease all throughout the life course, and in this regard re-emphasizes the resolve:

(a) To progressively cover persons living with a rare disease with quality essential health services and quality, safe, effective, affordable, and essential

<sup>8</sup> Resolution 70/1.

medicines, diagnostics, and health technologies, with a view to covering all persons living with a rare disease by 2030;

(b) To stop the rise and reverse the trend of catastrophic out-of-pocket health expenditure by providing measures to ensure financial risk protection and eliminate impoverishment due to health-related expenses by 2030, with special emphasis on persons living with a rare disease;

11. *Encourages* Member States to take appropriate steps to provide affordable, accessible and good-quality care facilities for children and other dependants living with a rare disease and measures promoting the equal sharing of household responsibilities between women and men, recognizing, reducing and redistributing women's and girls' disproportionate share of unpaid care and domestic work when a member of the family lives with a rare disease, and fully engaging men and boys as agents and beneficiaries of change and as strategic partners and allies in this regard;

12. *Also encourages* Member States to promote access to full and productive employment and decent work for persons living with a rare disease and their families by addressing challenges in access to, retention of and return to employment, inter alia, through the improvement of working conditions for persons living with a rare disease and their families, expanding flexible working arrangements, including through the use of new information and communications technologies, and providing and/or expanding leave arrangements, such as sick leave and carer's leave, and adequate social security benefits for both women and men, taking appropriate steps to ensure that they are not discriminated against when availing themselves of such benefits;

13. *Further encourages* Member States to eliminate barriers faced by persons living with a rare disease and their families in accessing water, sanitation and hygiene, including physical, institutional, social and attitudinal barriers, and to promote appropriate measures in cities and other human settlements that facilitate such access for persons living with a rare disease and their families, on an equal basis with others, in both rural and urban areas;

14. *Requests* the Secretary-General, in close collaboration with the Director General of the World Health Organization, to present a report to address, inter alia, the challenges faced by persons living with a rare disease and their families, to be submitted during the seventy-eighth session of the General Assembly;

15. *Decides*, considering the multifaceted nature of the challenges faced by persons living with a rare disease, to consider the issue of persons living with a rare disease at its seventy-eighth session, under the item entitled "Social development".