

**Special Rapporteur on the Rights of Persons with Disabilities**

**Independent Expert on the Enjoyment of all Human Rights by Older Persons**

**Expert Group Meeting**

**Supporting Autonomy and Independency of Older Persons with Disabilities**

**25-26 October 2017**

**United Nations Headquarters, New York**

**SUMMARY NOTE**

1. **INTRODUCTION**

The Special Rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas, and the Independent Expert on the enjoyment of all human rights by older persons, Ms. Rosa Kornfeld-Matte, hosted the first *Expert group meeting on supporting the autonomy and independency of older persons with disabilities* in New York in October 2017, with the support of the Government of Finland.

The expert meeting aimed to discuss the intersectionality between disability and ageing in the exercise of autonomy and independency, and to explore the potential of international and regional human rights instruments, in particular the UN Convention on the Rights of Persons with Disabilities (CRPD), to ensure their access to accessible, appropriate and affordable community-based support services.

The specific objectives of this meeting were:

1. Explore the intersections of ageing, disability and support;
2. Identify progress, gaps and challenges in the implementation of existing international and regional human rights frameworks in relation to the autonomy and independence of older persons with disabilities;
3. Identify progress, gaps and challenges in the provision of support services and assistive technologies for older persons with disabilities;
4. Identify practices for supporting the autonomy and independence of older persons with disabilities; and
5. Strengthen the collaboration between the organizations of older persons and persons with disabilities.

The expert group meeting hosted 25 experts from UN entities, organizations of persons with disabilities and older persons, civil society and academia, with a variety of expertise, perspectives, and regional representation.

1. **SUMMARY OF THE SESSIONS**

**Session 1: Ageing and disability: multiple discrimination and intersectionality**

A significant number of persons with disabilities, particularly in high-income countries, are older persons, which reflects the sustained ageing of the global population, as well as the increased life expectancy of persons with disabilities. The presence and **prevalence of disabilities increases with age** although many older people with disabilities may not self-identify as persons with disabilities, or do not even wish to be associated with the identity of being an older person.

The experts highlighted that older persons with disabilities face **exclusion and multiple layers of discrimination** based on their disability and their age. However, despite higher rates of disability in older persons, little or no attention is given to their particular situation. The **deprivation of legal capacity and institutionalization** were identified as specific forms of discrimination and violations of their rights. The experts highlighted that someone is more likely to be placed underguardianship if s/he is an older person with disabilities. They added that medical services are denied more often to older persons with disabilities than to younger persons with disabilities, also than compared to just older persons. Further, the experts identified the intersectionality between ageing and disability in the discussion of other issues as dementia, active participation in society, and the end‑of‑life issues.

Regarding the **human rights framework**,there isno international convention on the rights of older persons yet. However, the *Convention on the Rights of Persons with Disabilities (CRPD)* challenges substituted decision-making (Art. 12), involuntary treatment (Art. 15, 17) and institutionalization (Art. 19), which are common practices that restrict the rights of older persons with disabilities. The CRPD can also ensure their access to community-based support services and arrangements (Art. 19, 25). The *Inter-American Convention on the Human Rights of Older Persons*, whichalso incorporates these regulations, prohibits discrimination based on the age of older persons, establishing that State parties should develop specific approaches for people who are vulnerable or victims of multiple discrimination, including persons with disabilities, among other identities (Art. 5).

With respect to the main **gaps,** experts identify the **lack of a perspective of disability with aging or aging with disability in public policies and legislation**. In this sense, there needs to be a principle of inter-institutional coordination to design, implement and monitor policies related to older persons with disabilities. Furthermore, different **legislations** include **arbitrary and discriminatory age-related provisions**, reflecting the negative perceptions of aging. Likewise, anti‑discrimination laws in many countries do not have provisions covering discrimination based on age. National laws are often based on **single grounds of discrimination**, which makes multiple discrimination claims very difficult to make. This is the case when age and disability interact with other grounds of discrimination, such as gender, ethnicity or economic status. For instance, older women with disabilities often are victims of multiple and intersectional discrimination, including gender-based violence and abuse.

Furthermore, there is a **lack of** **internationally comparable and disaggregated data** on the situation of older persons with disabilities, since this data is not consistently collected or reported on. Consequently, disability and ageing remain invisible in mainstream development agendas and processes. Experts called for enhanced cooperation between the older persons movement and the movement of persons with disabilities, as well as more participation of older persons with disabilities in these discussions.

**Session 2: Autonomy and legal capacity**

Older persons with disabilities face multiple and intersecting forms of discrimination, particularly in exercising their autonomy and independence. They are at heightened risk of **denial or restriction of their legal capacity**, **involuntary treatment** and **institutionalization**. Experts provided examples of discriminatory legislation that consider age as a criterion for guardianship, or that allow the placement of older persons inresidential care settings without their informed consent.

In this regard, the *Convention on the Rights of Persons with Disabilities* recognizes **equal protection before law** of all persons with disabilities (including older persons with disabilities), thus changing the paradigm from “substitute” to “supported” decision-making (Art. 12), and challenging involuntary treatment (Art. 15, 17). Furthermore, the *Inter‑American Convention for the protection of human rights of the older persons* recognizes the right of older persons to make their own decisions (Art. 7).

With respect to the main **gaps and potential areas of tensions**, the experts noted the existence of **legal barriers** as well as **informal barriers** preventing the exercise of legal capacity, which are based on stereotypes associated with older persons with disabilities. In this sense, the *Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Older Persons* recognizes the right to make decisions but it also refers to “incapacitation”, which is a contradiction in itself.

Regarding **good practices in supported decision-making** for older persons with disabilities, legislation in Israel now contains references to supported decision-making regimes and advanced planning provisions. Likewise, Costa Rica adopted Law No. 9379, which abolished all forms of guardianship and created the legal figure of “guarantor for the equality before the law of persons with disabilities”, whose role is to ensure the full enjoyment of legal capacity by all persons with disabilities.

**Session 3: Living independently in the community**

Older persons with disabilities are at **heightened risk of institutionalization**, which increases with age. This leads to **social isolation**, exposing them to high levels of violence, abuse and neglect.According to the experts, independent living means dignity and autonomy, anda life outside of residential institutions. Indeed,institutionalization is one of the biggest **challenges** faced by older persons with disabilities, which imply the lack of control over day‑to‑day decisions and lack of choice over whom to live with. Another challenge is the **stigma** of disability in society, as well as the fact that laws protecting the rights of persons with disabilities are not applied to older persons.

In many countries, there are institutionsfor the “care” of older persons, with limited regulation. Experts identified that usually older persons **do not freely choose** to live in such places, but go there due to the lack of other options. This happens for instance if their house is not accessible, do not have families or friends in the community to support them, or there is a failing social service system. Furthermore, the independent living movement of older people remains very controlled by younger persons without disabilities. Disability experts called advocated for the use of the term “support” instead of “care”due to the connotation of dependency of the word “care” in relation to persons with disabilities.

In this context, States party to the *CRPD* have the obligation to enable older persons with disabilities to live independently in their communities (Art. 19). Disability experts associate “independent living” with “choice, control and support”. In its [General comment no. 5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en), the *CRPD Committee* stated that **every form of institutionalization is a human rights violation of persons** with disabilities, and that **community-based approaches** are the most adequate framework for the inclusion of older persons with disabilities. Moreover, the *Inter‑American Convention for the protection of human rights of the older persons* calls upon States to ensure that older persons have the opportunity to choose their place of residence, where and with whom to live, and access progressively community-support services (Art. 7).

In Israel for instance, older persons can choose between various kinds of living arrangements in the community, including assisted living in “senior” villages, supported neighborhoods, and greenhouse nursing homes. Cubahas a community model allowing older people to continue living in their home in accordance with their own decisions. They would however move to long‑term care institutions if they need intensive care and their life is at risk.

**Session 4: Assistive devices and technologies**

The **impact of assistive devices and technologies** on the rights of older persons with disabilities is fundamental. Many barriers they face in exercising autonomy relate to the absence of appropriate support services and assistive technologies. These include, among others, assistive devices, mobility aids, personal assistance, support in decision-making, and living arrangements services. Despite the rising demand for these services – related to the increase of demand by older people - the majority of older persons with disabilities have limited access to support services and rely on informal networks, primarily their families. When services do exist, they often do not respect their individual autonomy and independence, nor do they promote their full and effective participation and inclusion in society.

Experts considered the **gaps in accessibility and availability of technology and assistive devices** as a main challenge, as well as the lack ofparticipation of older persons with disabilities in the design of those technologies**.** Another challenge relates to **how older persons with disabilities can use technology to communicate**, and how to ensure their **consent** for using such tools. Experts stressed that choice and control means the right to refuse or to keep the technologies or devices once introduced. Other challenges include the fact that States **do not invest sufficiently** in support and autonomy, and older persons with disabilities do not get involved in such discussions.

Experts referred to examplesin Ireland**,** where a pilot project consists in testing different robotics technologies with persons with dementia, while explaining and obtaining their informed consent. InChile, a special phone enables older persons to communicate with other people through a set of screens. In Costa Rica a programme was started to reduce the digital gap among the aging population.

**Session 5: Moving forward: enhancing the attention on the rights of older persons with disabilities**

The *Convention on the Rights of Persons with Disabilities* has the potential to be interpreted from an ageing perspective, thereforeensuring **access to community-based support services and arrangements** for older persons with disabilities, including assistive devices and technologies. Furthermore, the *Convention* challenges widespread practices such as substituted decision-making, involuntary treatment and institutionalization, calling for a **human rights-based approach** to address the rights of older persons with disabilities.

Experts reinstated that it iscritical to collect **disaggregated indicators and statistics** that reflect the situation of older persons with disabilities. Understanding intersectionality is essential in order to make the right questions for data collection. Experts mentioned that since the establishment of the Inter-agency Expert Group on Sustainable Development Indicators, older persons and persons with disabilities struggled to have a space to deliver a joint statement. Experts stressed that disaggregation of data by age should not stop at 50 or 60 years, and that disaggregation by disability should be measured with the Short set of questions developed by [Washington Group on Disability Statistics](http://www.washingtongroup-disability.com/).

Finally, [Open-ended Working Group on Ageing for the purpose of strengthening the protection of the human rights of older persons](https://social.un.org/ageing-working-group/)has recognized the principles of “autonomy” and “independence” of older persons as a priority. Based on these principles of the *CRPD*, the disability perspective could be promoted in this Group. Experts agreed that the **cooperation** **between the older persons and disability communities** is fundamental, including in the area of advocacy, where the latter movement has more experience. This could result in increased the awareness and references on the rights of older persons with disabilities in the UN human rights machinery and its instruments, including the *CRPD.* For instance, experts noted that only 0.3% of all recommendations made in the UPR process to date focused on the rights of older persons. Furthermore, experts agreed about the need for the *CRPD Committee* to develop and adopt a General Comment on the rights of older persons with disabilities.

Experts also thought it is necessary to **increase the focus on older persons with disabilities in the 2030 Agenda** and to reaffirm their participation in sustainable development processes. It would also be important to identify where in the Agenda 2030 and related SDG there can be explicit references to older persons.

1. **CONCLUSIONS AND RECOMMENDATIONS**

Experts concluded that older persons with disabilities face exclusion, multiple and intersectional discrimination that lead to human rights violations, such as the deprivation of legal capacity and institutionalization. In this context, the *CRPD* has the potential of advancing the rights of older persons with disabilities because it challenges substituted decision-making regimes, involuntary treatment and institutionalization. The *CRPD* can also ensure their access to community-based support services and arrangements. These regulations have been already incorporated into the *Inter-American Convention on the Human Rights of Older Persons*.

Some of the gaps identified during the meeting include: the lack of standards on the rights of older persons with disabilities, the lack of a disability perspective with aging (or aging with disability) in public policies, legislation with arbitrary age provisions, the negative image of aging, the lack of disaggregated data on older persons, and insufficient participation of older persons with disabilities in these discussions.

Independent living means dignity and autonomy, a life outside of residential institutions for older persons with disabilities. Under the *Convention on the Rights of Persons with Disabilities*, community-based approaches are the most adequate framework for the inclusion of older persons with disabilities. Many barriers faced by older persons with disabilities in exercising autonomy relate to the absence of appropriate support services and assistive technologies. They have limited access to support services and rely on informal networks, primarily their families. When services do exist, they often do not respect their autonomy, nor do they promote their full and effective participation and inclusion in society.

Finally, cooperation between the older persons and disability communities is fundamental to enhance the focus on older persons with disabilities in the 2030 Agenda, promote a disability perspective in the discussions in the Open-Ended Working Group on Ageing, and increase references to older persons with disabilities in UN human rights mechanisms.

Experts also recommended that the CRPD Committee develops and adopts a General Comment on focusing on the rights of older persons with disabilities.