



Open for Consultation
Human Rights Principles That Matter to Older Persons
Derived from the 2026 Global Rally Event: *Who Decides?*

Prepared by Age Knowble
Convener of the 2026 Global Rally Event and this Consultation
Informing the Development of the UN Convention on the Rights of Older Persons
Consultation Period: 11 March to 15 April 2026

I. Overview

At the 2026 Global Rally Event, *Who Decides? Human Rights Principles That Matter to Older Persons with Dementia*, older persons living with dementia, caregiver, organisations serving older persons with dementia, together with clinical, ageing policy, human rights experts, and rally participants, examined a central question:

Who decides when cognitive abilities change in older age?

Across regions and roles, the dialogue revealed a shared concern: diagnosis too often narrows voice, participation, and recognition. From lived experience and system perspectives, six human rights principles emerged.

These principles affirm that dementia does not diminish personhood, does not justify the removal of legal capacity on the basis of diagnosis, does not legitimise discrimination, and does not permit protection to replace agency. They also identify the safeguards and accountable public systems required to realise rights in practice.

This Consultation Brief synthesises the dialogue and presents the human rights principles and Convention imperatives derived from it. It now invites broader input on:

- The six principles identified in relation to older persons with dementia
- The applicability of these principles across older age more broadly
- The imperatives and cross-cutting themes that should guide the development of a UN Convention on the Rights of Older Persons

This Brief Presents:

1. Cross-group comparative analysis of the Rally event dialogue across lived experiences, civil society, and system expertise P.2
2. An examination of personhood in older age as the moral foundation of rights P.5
3. Six principles with substantive implications for a UN Convention on the Rights of Older Persons P.5
4. Cross-cutting themes applicable across all principles P.7
5. Convention imperatives identified through the dialogue P.8
6. Acknowledgement of contributors and access to the full Rally event recording P.8
7. A global online consultation on human rights principles that matter to older persons — including older persons with dementia and across older age P.9

II. Cross-Group Comparative Analysis

The six principles presented in this Brief were distilled from dialogue across three groups during the 2026 Global Rally Event:

- Older persons living with dementia (Canada, Singapore)
- A caregiver and organisations serving older persons with dementia (Africa, Asia Pacific)
- Clinical, policy, and human rights experts (India, Europe, Croatia)

The dialogue across lived experiences, civil society, and system-level expertise revealed strong areas of convergence alongside contextual variation in emphasis and manifestation. Importantly, differences across regions reflected variation in governance capacity, infrastructure, and public awareness — not differences in the universality of rights.

Cross-Group Comparison: Human Rights Principles That Matter to Older Persons with Dementia

Principles	Self-Advocates (Lived Experience)	Caregiver & NGOs (Africa & Asia-Pacific)	System Experts (Clinical, Policy, Human Rights Oversight)	Convergence	Contextual Variation in Emphasis
1. Recognition of Personhood and Continued Identity	Diagnosis should not erase identity. Continued roles, aspirations, and contributions remain possible.	Risk of silencing within families and communities. Loss of visibility due to stigma or fear.	Personhood and autonomy are non-negotiable. Even when family support is essential, the individual's voice must remain primary.	Strong agreement that diagnosis must not erase personhood, identity, or rights-holder status.	In some contexts, personhood is gradually eroded through social sidelining and lowered expectations. In others, it may be erased through stigma, misinterpretation, or severe harm.
2. Legal Capacity and Supported Decision-Making	Consent disregarded or dismissed. Decisions are made for rather than with the person. Capacity is treated as all-or-nothing.	Families often assume decision-making authority out of a sense of protection, cultural norms, or a lack of awareness of supported alternatives.	Presumption of capacity must be the starting point. Supported decision-making safeguards are essential to prevent arbitrary substitution.	Across contexts, diagnosis is frequently treated as sufficient justification for substituted decision-making, resulting in the narrowing or removal of legal capacity in practice.	In some contexts, legal capacity is gradually eroded through informal family substitution and lowered expectations. In others, it may be formally removed through guardianship or legal mechanisms triggered by diagnosis.

Principles	Self-Advocates (Lived Experience)	Caregiver & NGOs (Africa & Asia-Pacific)	System Experts (Clinical, Policy, Human Rights Oversight)	Convergence	Contextual Variation in Emphasis
3. Freedom from Ageism and Discrimination	Exclusion from social and professional roles following disclosure. Lowered expectations and assumptions of incapacity after diagnosis.	Dementia is often poorly understood due to limited public awareness and persistent stigma. In some contexts, symptoms are misinterpreted, contributing to marginalisation, abandonment, or, in extreme cases, violence.	Ageism embedded in health and care systems normalises decline and lowers expectations. Dementia stigma delays diagnosis, restricts access to services, and reinforces discrimination.	Across contexts, dementia stigma and ageism operate as structural drivers of discrimination, exclusion, and unequal treatment.	Manifestations range from subtle social exclusion and professional sidelining to denial of services, institutional neglect, and, in some contexts, severe violence.
4. Inclusion and Participation	Continued engagement is possible across work, advocacy, and community life. Participation narrows after diagnosis unless actively supported.	Community inclusion reduces isolation and fear. Examples include dementia-friendly initiatives, youth engagement, and involvement of persons with dementia in publications and advocacy.	Participation requires accessible information, inclusive consultation mechanisms, and institutional safeguards to ensure ongoing involvement in decision-making.	Strong agreement that participation must remain meaningful and accessible after diagnosis. Without safeguards, it narrows in practice. Inclusion is essential to dignity and rights realisation.	Strong agreement that participation must remain meaningful and accessible after diagnosis. Without safeguards, it narrows in practice.
5. Protection from Violence and Harm with Dignity	Protective measures imposed without consultation. Social or professional exclusion justified as “for safety.” Loss of choice following diagnosis.	Exposure to neglect, abuse, and unsafe environments where safeguards are weak. In some contexts, older persons face severe harm due to stigma or lack of protection.	Protection must be proportionate and rights-based. Safeguards, oversight, and consent mechanisms are essential to prevent arbitrary restriction or institutionalisation.	Strong agreement that protection is necessary but must not override autonomy or justify arbitrary restriction.	In some contexts, risk aversion leads to over-restriction or institutionalisation without adequate safeguards. In others, weak protection systems expose individuals to neglect or violence.

Principles	Self-Advocates (Lived Experience)	Caregiver & NGOs (Africa & Asia-Pacific)	System Experts (Clinical, Policy, Human Rights Oversight)	Convergence	Contextual Variation in Emphasis
6. State and Community Obligations for the Realisation of Rights	Continued contribution depends on accessible systems and inclusive environments. Barriers arise when systems fail to adapt.	Continued contribution depends on accessible systems and inclusive environments. Barriers arise when systems fail to adapt.	The realisation of rights depends on States establishing and maintaining accountable governance structures, enforceable safeguards, trained workforces, accessible services, and effective remedies. Without institutional oversight and public awareness, rights remain theoretical rather than lived.	Strong agreement that rights are universal, but their realisation depends on public systems, governance capacity, and community awareness.	Strong agreement that rights are universal, but their realisation depends on public systems, governance capacity, and community awareness.

The comparative analysis demonstrates three structural findings:

1. **Diagnosis-based erosion of rights is a shared concern.**
Across settings, disclosure of dementia frequently triggers narrowing of participation, voice, or decision-making authority — whether subtle or severe.
2. **Legal capacity and participation are interdependent in practice.**
Without safeguards for supported decision-making, participation narrows in practice. Where capacity is presumed and supported, participation expands.
3. **Public systems determine whether rights are realised.**
Differences across contexts relate to governance capacity and system infrastructure, not to the universality of rights.

These findings inform the principles that will follow.

III. Personhood in Older Age: Moral Foundation and Lived Reality

Human rights begin with recognition of the person.

The dialogue affirmed that dementia does not diminish personhood. Older persons living with dementia remain full rights-holders whose identity, history, relationships, and aspirations persist despite cognitive change.

Personhood becomes fragile when:

- Diagnosis triggers assumptions of incapacity
- Decisions shift without participation
- Protection replaces autonomy
- Silence replaces voice

Recognition of personhood requires:

- Continued acknowledgement of identity
- Respect for expressed preferences within capacity
- Support where needed without substituting voice
- Opportunities for meaningful engagement

Recognition of personhood provides the foundation for the human rights principles that follow, which reflect what matters most to older persons when cognitive abilities change in later life.

IV. The Six Human Rights Principles

The following human rights principles provide guidance for the development of human rights standards and corresponding State obligations within a future Convention on the rights of older persons. Each principle is presented with three elements:

- Issue Revealed
- Dialogue Reflected
- Principles Affirmed

Principle 1 — Recognition of Personhood and Continued Identity

Issue Revealed

Diagnosis often triggers assumptions of diminished identity, capability, or social relevance.

Dialogue Reflected

Participants described being sidelined following disclosure, while emphasizing that roles, aspirations, and contributions continue despite diagnosis.

Principle Affirmed

Personhood and identity persist across cognitive change and need to be recognised and respected in law, policy, and practice.

Principle 2 — Legal Capacity and Supported Decision-Making

Issue Revealed

Diagnosis is frequently treated as sufficient justification for substituted decision-making.

Dialogue Reflected

Consent disregarded; decisions made for rather than with the person; capacity treated as all-or-nothing.

Principle Affirmed

Legal capacity must not be removed solely on the basis of a diagnosis. Support should be provided where needed.

Principle 3 — Freedom from Ageism and Discrimination

Issue Revealed

Dementia stigma and ageism drive exclusion and rights violations.

Dialogue Reflected

Participants described marginalisation, loss of roles, and, in some contexts, serious harm linked to stigma and misinterpretation.

Principle Affirmed

Exclusion or unequal treatment based on age or cognitive change constitutes discrimination.

Principle 4 — Inclusion and Participation

Issue Revealed

Participation often narrows following diagnosis unless actively supported through accessible and inclusive mechanisms.

Dialogue Reflected

Older persons with dementia demonstrate continued engagement and contribution. Barriers to accessibility limited meaningful participation.

Principle Affirmed

Participation must remain meaningful, accessible, and supported through appropriate laws, policies, and institutions.

Principle 5 — Protection from Violence and Harm with Dignity

Issue Revealed

Protection measures may become overly restrictive or dismissive of autonomy when not properly safeguarded.

Dialogue Reflected

Participants described risks of neglect, abuse, restraint, and institutionalisation without adequate safeguards.

Principle Affirmed

Protection must be proportionate, rights-based, and dignity-centred.

Principle 6 — State and Community Obligations to Enable the Realisation of Rights

Issue Revealed

The realisation of rights depends on governance capacity, institutional safeguards, public awareness, and accessible services.

Dialogue Reflected

Where systems were weak, exclusion and caregiver strain increased. Where public frameworks were stronger, rights were more consistently realised.

Principle Affirmed

Realisation of rights requires accountable public systems. This includes oversight, quality standards, trained professionals, accessible services, and complaint mechanisms. Community awareness and caregiver recognition are important, but do not replace State responsibility.

VI. Cross-Cutting Themes

Three foundational themes apply across all six principles:

1. Dignity

Dignity underpins recognition, participation, protection, and non-discrimination. It requires that the rights of older persons be upheld without conditionality.

2. Self-Determination

Self-determination is the retention of agency and the ability to make decisions, including through supported decision-making where needed. Diagnosis cannot displace self-determination.

3. Accountability

Accountability means that rights must be enforceable. Monitoring, oversight, complaint mechanisms, and access to justice are essential to implementation.

VI. Convention Imperatives

Building on the six principles, the dialogue also identified several core imperatives to guide the drafting of a future Convention on the Rights of Older Persons.

- **Affirm the continuing personhood and full rights-holder status of older persons**, ensuring that their rights cannot be diminished on the basis of diagnosis or changes in cognitive or functional ability.
- **Guarantee recognition of legal capacity**, prohibit diagnosis-based exclusion, and require supported decision-making safeguards.
- **Address ageism and dementia-related stigma as structural drivers of discrimination**, with preventive and remedial measures.
- **Provide for inclusive consultation mechanisms**, accessible information, and meaningful participation of older persons in decisions affecting them.
- **Mandate safeguards against abuse and arbitrary confinement**, ensuring protective measures remain proportionate, rights-based, and dignity-centred.
- **Establish accountable public systems** with governance structures, trained workforces, accessible services, and monitoring mechanisms to operationalise rights in practice.
- **Ensure access to justice, effective remedies, and independent oversight mechanisms.**
- **Recognise the diversity of older persons**, including differences in age, gender, disability or functional ability, culture, socio-economic context, and other life situations.

VII. Acknowledgement and Next Steps

Convening and Acknowledgements

Age Knowble convened the 2026 Global Rally Event, *Who Decides? Human Rights Principles That Matter to Older Persons with Dementia*, and synthesised the dialogue reflected in this Consultation Brief. We acknowledge and thank all contributors to the Global Rally Event. The insights and perspectives shared informed the principles and analysis presented in this Brief.

Keynote Speakers

Nataša Todorović | Global Alliance for the Rights of Older People
DY Suharya | Alzheimer's Disease International

Panelists

Emily T.T. Ong | Lived Experience Expert, Singapore
Jim Mann | Lived Experience Expert, Canada
Debanjan Banerjee | APOLLO Multispecialty Hospitals, Kolkata
DY Suharya | Alzheimer's Disease International
Monica Kinyanjui | Women for Dementia Africa
Tatjana Vlašić | Deputy Ombudswoman of the Republic of Croatia
Yongjie Yon | World Health Organization, Regional Office for Europe

Participation at a Glance

249 Registrants | 140 Attendees [Zoom Statistics]

Zoom Technical Host

Osnat Lustig | Pass It On Network

Co-Sponsors

ASEM Global Ageing Center ♦ International Federation of Settlement Houses and Neighborhood Centers ♦ International Longevity Center Global Alliance ♦ NGO Committee on Ageing Geneva
NGO Committee on Ageing New York ♦ Pass It On Network ♦ Stakeholder Group on Ageing ♦ Stakeholder Group on Ageing, Africa

Record of the Global Rally Event

The full video record of the 2026 Global Rally Event is available here. It is provided for reference:
<https://youtu.be/TjuFh3TuMYg>

Next Steps

Building on the dialogue from the Global Rally and the analysis that followed — which identified personhood, human rights principles, cross-cutting themes, and drafting imperatives — Age Knowble is convening this consultation to gather broader input on the human rights principles that matter to older persons, including those living with dementia.

The consultation will contribute to a consolidated submission to inform the development of a future UN Convention on the Rights of Older Persons.

IX. Consultation Invitation

Age Knowble invites you to participate in an online consultation exploring the human rights principles, cross-cutting themes, and drafting imperatives that matter to older persons in the development of a future UN Convention on the rights of older persons.

The consultation seeks to validate and strengthen insights identified through the Global Rally dialogue on the human rights of older persons living with dementia, and to examine whether and how these insights apply more broadly to older persons.

We welcome input from people of all ages — including older persons, caregivers, family members, organisations, professionals, researchers, policymakers, national human rights institutions, and anyone interested in how dignity and rights are experienced in older age.

Online Consultation Form: <https://s.surveypplanet.com/510g29xi>

Deadline: 15 April 2026

This consultation is convened and coordinated by Age Knowble. All contributions will be synthesised into a consolidated submission to inform the development of a UN Convention on the Rights of Older Persons.