

OUR VOICES, OUR RIGHTS

WHAT OLDER PEOPLE SAY ABOUT THE NORMATIVE ELEMENTS OF THEIR RIGHT TO AUTONOMY AND INDEPENDENCE

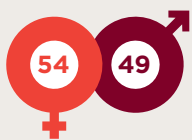
BANGLADESH



Older people in Bangladesh value their autonomy and independence and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 104 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



104 in total:
54 women
49 men
1 skipped the question



88% urban
12% rural



23% with disabilities

Deciding where and with whom to live

Fifty-three per cent of participants said having the freedom to decide where and with whom to live was very important or important.

'Without human rights and individual freedom, quality of life is degraded and dignity is lost.'
61-year-old man

Living where they chose made them 'feel better', improved their 'quality of life' and gave them 'dignity'.

Making decisions about what matters in life

Sixty-five per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. This 'empowered' them and 'made them feel better'. Life would be 'a misery' or 'worthless' if they did not have this freedom.

'Without freedom, life is worthless.'
55-year-old woman

Autonomy and independence in everyday activities and participation in society

Sixty-nine per cent said it was very important or important to carry out everyday activities based on their own will and preferences. They said they felt 'satisfied' and their 'mind was at peace'. It was 'wonderful' or 'joyous' to be able to make their own choices, and important to 'express their personal opinion'.

'Yes! We have our own opinions.'
51-year-old woman

Deciding about care and support services

Sixty-seven per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'Without freedom of choice, I couldn't get the care service I wanted.'
75-year-old man

Supported decision-making

Seventy-two per cent said having access to support for making decisions about their care and support was very important or important to them.

Sixty-eight per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Seventy per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Sixty-eight per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. This was important because they felt palliative care was 'necessary at the end of life'. It would improve the 'quality' and 'dignity of the last stage of life'.

'[I want a] natural death without pain; nobody [will] laugh at me.'
67-year-old man



Abir Abdullah/Age International

Overall response by gender

Men value their autonomy and independence more highly than women do. On average, 89 per cent of men and 47 per cent of women said it was very important or important to them.¹

Official recognition of rights by the government or the United Nations

Seventy-three per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.²

'It's the government's responsibility to ensure citizens' rights.'
71-year-old woman

Recognition would remove 'barriers' they faced to making decisions and enable them to 'voice their opinions'. Older people would be 'valued' and 'accepted' more. Recognition would lead to 'better treatment before death', 'reduce arguments among families and the government' about what action to take, and bring 'peace' to the older person.



Abir Abdullah/Age International

1. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.

2. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

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CAMEROON



Older people in Cameroon value their autonomy and independence very highly and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 100 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



100 in total:
51 women
49 men



50% urban
49% rural



84% with disabilities

Deciding where and with whom to live

Ninety-nine per cent of participants said having the freedom to decide where and with whom to live was very important or important. Having this freedom meant they were 'free to live their own life' and were 'responsible'. They felt 'happy' and a 'full person'. They had their 'liberty'.

'I am a person living in liberty.'
64-year-old woman

Making decisions about what matters in life

Every participant said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. Having freedom to make these decisions made them 'feel at ease'. It gave them 'power'. They felt 'respected' and able to 'play all parts of life'.

'I am considered a human being with rights.'
76-year-old woman

Autonomy and independence in everyday activities and participation in society

Every participant said it was very important or important to carry out everyday activities based on their own will and preferences. Having freedom to carry out these activities as they wished was important to be 'integrated in the community', lead a 'normal life', be 'independent' and not feel 'useless'.

'It means that I am able to exploit my potential.'
70-year-old woman

Deciding about care and support services

Ninety-seven per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'It's good for me. I decide if it's necessary or not.'
68-year-old man

Supported decision-making

Ninety-eight per cent said it was very important or important to have access to support for making decisions about their care and support.

Ninety-nine per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Ninety-nine per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Ninety-seven per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. Freedom to choose their palliative care was important because they 'have that right'. They wanted 'to have a good end of life', 'to die without pain' and 'in peace', and to end their life 'with dignity' and 'in control'.

'I am free even at the end of my life.'
66-year-old man

Overall response by gender

Women and men value their autonomy and independence equally highly. On average, 99 per cent of women and 98 per cent of men said it was very important or important to them.²

Official recognition of rights by the government or the United Nations

Ninety-nine per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.³

Recognition would 'change their lives'. It would lead to 'better treatment' and necessary 'practical assistance'. Other people would 'know and respect' their rights. They could live 'with dignity' and would not be 'discriminated against'.

'It gets to prove that I am a citizen of my country.'
70-year-old woman



ACAMAGE



ACAMAGE

1. 1% answered 'I don't know'.
2. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
3. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by Association Camerounaise pour la Prise en charge des Personnes Agées (ACAMAGE)

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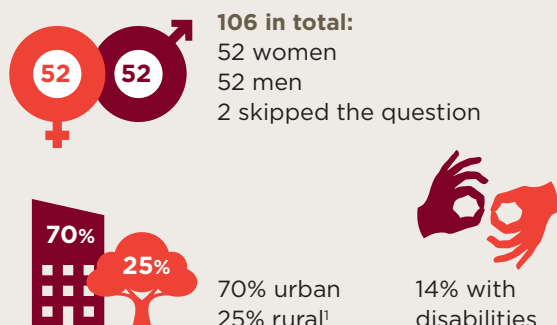
INDIA



Older people in India value their autonomy and independence highly and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 106 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



Deciding where and with whom to live

Eighty-nine per cent of participants said having the freedom to decide where and with whom to live was very important or important because it was a 'personal' decision and they could 'decide what sort of life to lead'. It gave them 'self-respect' and 'self-esteem'. It was important for both 'physical and mental stability'.

'Otherwise it would be like being a caged bird or animal.'
67-year-old man

Making decisions about what matters in life

Ninety-eight per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. This made them feel 'independent and wanted' and 'valued' by others. It gave them 'pleasure and satisfaction'.

'It gives me a sense of identity and freedom.'
57-year-old woman

Autonomy and independence in everyday activities and participation in society

Ninety-five per cent said it was very important or important to carry out everyday activities based on their own will and preferences. This gave them 'satisfaction' and 'happiness'. It made them feel 'capable' and 'not a burden'. It gave them 'self-confidence' and was part of being 'human'.

'[Being] unable to carry out activities as I wish means I am imprisoned or incapacitated.'
67-year-old man

Deciding about care and support services

Ninety per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'You will be the best judge of the support services you need at this age.'
67-year-old man

Supported decision-making

Eighty-six per cent said it was very important or important to have access to support for making decisions about their care and support.

Eighty-five per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Seventy-three per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Seventy-nine per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. This brought 'peace of mind' and 'confidence there was an option for the future'. It 'indicated their autonomy' and 'free will'.

'I should be able to avail it and stop it if I feel like it.'
65-year-old woman

Overall response by gender

Women and men value their autonomy and independence equally highly. On average, 86 per cent of women and 89 per cent of men said it was very important or important to them.²

Official recognition of rights by the government or the United Nations

Seventy-six per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.³

Recognition was important as older people's rights needed to be 'valued' and the 'government had a major role' to 'improve policies'. Recognition could 'influence the public and bring about a change in society'. It was the government's and United Nation's duty 'to set standards' and 'enforce the law'.

'The international laws which are designed to protect our rights will definitely make our country's law stronger, better and more effective.'
66-year-old woman



Sion Jones/
HelpAge International



Sion Jones/
HelpAge International

1. 4% answered 'Other' and 1% 'I prefer not to say'.
2. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
3. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by the Centre for Gerontological Studies (CGS)

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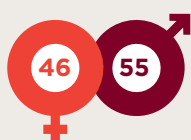
KENYA



Older people in Kenya value their autonomy and independence highly and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 101 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



101 in total:
46 women
55 men



23% urban
68% rural



55% with disabilities

Deciding where and with whom to live

Ninety-eight per cent of participants said having the freedom to decide where and with whom to live was very important or important. Having this freedom was important because they could live in 'a set-up they admire', could do 'all they wish to do', 'fulfil their desires', 'exercise their freedom' and live 'comfortably', 'free from stress'.

'I could lead my own life and enjoy autonomy.'
68-year-old man

Making decisions about what matters in life

Ninety-seven per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. Having this freedom allowed them to 'meet their goals'. It made them feel 'comfortable' without any 'pressure'.

'It means living a life of my choice.'
84-year-old woman

Autonomy and independence in everyday activities and participation in society

Ninety-seven per cent said it was very important or important to carry out everyday activities based on their own will and preferences. Having the freedom to carry out these activities as they wished enabled them to 'avoid stress' and live 'a happy life' with no need 'to bother anyone'.

'My life becomes mine and my wishes remain as I wish.'
87-year-old man

Deciding about care and support services

Ninety-nine per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'There would be freedom of choice.'
72-year-old man

Supported decision-making

Ninety-four per cent said it was very important or important to have access to support for making decisions about their care and support.

Ninety-seven per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Eighty-five per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Ninety-six per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. This was important as they would get 'the care they needed', 'at the right time', 'from a qualified person' and 'from a caregiver of their choice'.

'I shall get the services required and be able to have my choice which I am comfortable with.'
81-year-old man

Overall response by gender

Women and men value their autonomy and independence equally highly. On average, 95 per cent of women and 96 per cent of men said it was very important or important to them.²

Official recognition of rights by the government or the United Nations

Ninety-nine per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.³

Recognition would mean that their rights would be 'secured in the law'. Their freedom would be 'safeguarded' and they could 'demand their rights'. The government could be 'held accountable' and older people would not be forced 'to do what they don't like doing'.

'I would have freedom to exercise my right without fear because I would be protected by law.'
79-year-old woman



Roopa Gogineni



HelpAge International

1. 9% answered 'Other'.
2. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
3. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

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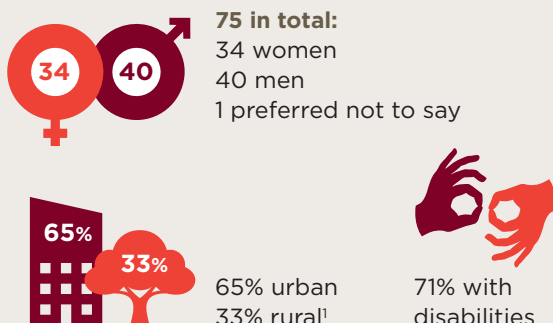
LIBERIA



Older people in Liberia value their autonomy and independence highly and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 75 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



Deciding where and with whom to live

Ninety-three per cent of participants said having the freedom to decide where and with whom to live was very important or important. It meant they could choose 'a better place' and who could 'come and live in their house'. Choosing this themselves would make them 'happy'.

'It means I can be around the people I want to be with and stay in the house I want.'
69-year-old man

Making decisions about what matters in life

Ninety-one per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. This meant they could make decisions 'to improve their life' and not have 'other people decide for them.'

'It means I'm free to decide what's good for me.'
73-year-old woman

Autonomy and independence in everyday activities and participation in society

Ninety-five per cent said it was very important or important to carry out everyday activities based on their own will and preferences. It enabled them to 'do the things they wanted every day' 'without interference' or 'people telling them what to do'.

'It means a lot for me to go out every day and do the things I like to do, although I'm old now.'
72-year-old woman

Deciding about care and support services

Every participant said it was very important or important to make their own decisions about their care and support, including planning ahead for future support. They could access services that were 'good for them', would keep them 'healthy and happy' and 'help their family care for them'.

'I can get the services I need to keep me strong until I die.'
60-year-old woman

Supported decision-making

Every participant said it was very important or important to have access to support for making decisions about their care and support.

Every participant said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Every participant said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Every participant said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. This was important as they felt they could 'freely choose' the palliative care 'that is good for them when they need it'.

'Of course, we do not know about palliative care in Liberia, but it's important for it to be available to older people.'
58-year-old man

Overall response by gender

Women and men value their autonomy and independence equally highly. On average, 98 per cent of both women and men said it was very important or important to them.²

Official recognition of rights by the government or the United Nations

Ninety-nine per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.³

Recognition meant the government would 'respect' their rights and would 'provide services'. It meant decisions would not be taken 'for them without them taking part'. They would not be 'taken advantage of'. They would be 'treated as an adult' and treated well 'no matter their age'.

'I can be respected and treated as a human being.'
78-year-old woman



CECAFE



Jemma Stovell/
HelpAge International

1. 65.33% urban, 33.33% rural, 1.33% don't know.
2. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
3. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

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MAURITIUS



Older people in Mauritius value their autonomy and independence highly and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 100 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



100 in total:
50 women
50 men



46% urban
52% rural¹



17% with
disabilities

Deciding where and with whom to live

Eighty-one per cent of participants said having the freedom to decide where and with whom to live was very important or important because 'freedom was a right'. They could continue being 'independent' and 'keep their identity'. Everyone in the family should have 'equal recognition'.

'Choosing for myself would mean recognising my dignity.'
72-year-old man

Making decisions about what matters in life

Ninety per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. It meant they would still be 'valued in the eyes of others' and their 'wishes were respected'. It meant they 'do things at their own pace' which was 'essential for happiness'.

'The day I don't have this freedom I will feel useless and helpless.'
80-year-old woman

Autonomy and independence in everyday activities and participation in society

Ninety-five per cent said it was very important or important to carry out everyday activities based on their own will and preferences. This made them 'feel autonomous', 'accomplished' and 'useful to their family' and 'to society'. They did not want to 'feel like a prisoner' but to 'continue being independent' and 'equal'.

'Without the freedom, I would not feel equal to my husband.'
60-year-old woman

Deciding about care and support services

Ninety-one per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'Although I'll ask the opinion of my family, in the end I'll make the final choice.'
66-year-old man

Supported decision-making

Eighty-eight per cent said it was very important or important to have access to support for making decisions about their care and support.

Eighty-four per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Seventy-one per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Ninety per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. They could 'plan for a better end of life', 'suffer less' and 'die without pain'. They would feel 'more at ease with the treatment or therapy'.

'To die peacefully, being conscious I made the choice.'
72-year-old man

Overall response by gender

Men value their autonomy and independence slightly more than women. On average, 90 per cent of men and 83 per cent of women said it was very important or important to them.²

Official recognition of rights by the government or the United Nations

Seventy-nine per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.³

Recognition meant 'rules couldn't be imposed to control their movement', older people would be 'fully integrated into society', the government would introduce 'additional laws', and rights would be 'guaranteed'. Older people's 'voices needed to be heard'.

'They should know that even in a [residential care] home we must have the right to autonomy.'
90-year-old woman



DIS-MOI



DIS-MOI

1. 1% answered 'Other' and 1% 'I prefer not to say'.
2. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
3. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

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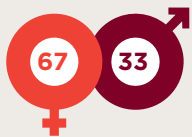
NEPAL



Older people in Nepal value their autonomy and independence and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 100 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



100 in total:
67 women
33 men



90% urban
5% rural¹



67% with disabilities

Deciding where and with whom to live

Seventy per cent of participants said having the freedom to decide where and with whom to live was very important or important to them. It was important for their 'happiness' and 'dignity'. They could 'be surrounded by loved ones' and live without 'pressure' or 'control' from someone else.

'It makes people happy and [gives] self-satisfaction. However, coming here [a residential care facility] is not what I wanted but I was alone and didn't have much choice.'
69-year-old man

Making decisions about what matters in life

Seventy-three per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. It gave them 'independence', 'dignity', 'confidence' and 'self-respect'. It meant they were not 'controlled by others'.

'Nobody likes to live a life depending on others. People should have freedom to live their life according to their wishes.'
68-year-old woman

Autonomy and independence in everyday activities and participation in society

Seventy-one per cent said it was very important or important to carry out everyday activities based on their own will and preferences.

This made them feel 'responsible' and 'active'. They could 'get involved in community activities' and 'live proudly and contribute to society'.

'It feels like being in prison when someone controls us.'
65-year-old woman

Deciding about care and support services

Seventy-four per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support. They would not have 'to rely on others' or 'be dependent'. They could 'enjoy life without restrictions' as 'nobody wants to live under someone's control'.

'If I can be involved in my support services, I will respect myself.'
62-year-old man

Supported decision-making

Sixty-six per cent said it was very important or important to have access to support for making decisions about their care and support.

Ninety-one per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Fifty-nine per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Fifty-six per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it.

'I can decide for myself without depending on others.'
84-year-old man

Overall response by gender

Men value their autonomy and independence more highly than women. On average, 90 per cent of men and 60 per cent of women said it was very important or important to them.²

Official recognition of rights by the government or the United Nations

Seventy-three per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.³

Recognition was important 'to ensure older people's fundamental rights' because 'many older people have not got freedom' and are 'dominated by family, society and community'. Recognition meant they could 'legally claim their right to palliative care' and 'enjoy their freedom to make decisions' and 'not depend on others' to make decisions for them.

'To be able to live freely despite being older.'
75-year-old man



Nepal Guido Dingemans/
HelpAge International



Judith Escribano/
Age International

1. 3% answered 'Other', 1% 'I don't know' and 1% 'I prefer not to say'.
2. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
3. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

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RWANDA



Older people in Rwanda value their autonomy and independence highly and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 142 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



142 in total:
86 women
56 men



52% urban
48% rural



44% with disabilities

Deciding where and with whom to live

Eighty-five per cent of participants said having the freedom to decide where and with whom to live was very important or important. This was important for their 'confidence'. They could 'age in peace'. It helped 'combat isolation' and made them feel 'respected and valued' and 'a human like others'.

'I'm free to decide where to live and whom to live with even [if it is] safe or not.'
78-year-old man

Making decisions about what matters in life

Eighty-seven per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. Having this freedom meant they would be 'independent' and 'respected'. It meant their 'ideas are worthy'.

'When someone limits you doing something you need to do, it shames you.'
59-year-old woman

Autonomy and independence in everyday activities and participation in society

Ninety-one per cent said it was very important or important to carry out everyday activities based on their own will and preferences. This made them feel 'stronger', 'useful', and 'productive and helpful in society'.

'It is very important because it connects me with other people living in my community.'
65-year-old woman

Deciding about care and support services

Eighty-seven per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'[This] is important because [I can choose] the support services matching my needs.'
60-year-old woman

Supported decision-making

Ninety per cent said it was very important or important to have access to support for making decisions about their care and support.

Ninety-six per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Seventy-seven per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Eighty-five per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. This meant they could exercise 'their right to be involved in their treatment'. It gave them 'hope' and would give them 'more options'.

'Even though I have never heard of palliative care here at home, I think it would be a very nice thing because it would allow people to choose how to live their last days.'
60-year-old woman

Overall response by gender

Women and men value their autonomy and independence equally highly. On average, 86 per cent of women and 89 per cent of men said it was very important or important to them.¹

Official recognition of rights by the government or the United Nations

Eighty-eight per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.²

Recognition was important as their families and communities would 'recognise' and 'have to respect' their rights. Recognition meant the government would put in place 'projects' and 'measures' to support older people's independence. Institutions would 'support their wishes'. No 'boundary or limit' would be placed on their activities.

'Because if they recognise this autonomy and they put it into practice, it could fulfil my dream of having an independent life.'
54-year-old man



Elle Parravani/
HelpAge International



Elle Parravani/
HelpAge International

1. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.

2. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by NSINDAGIZA Organisation

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OUR VOICES, OUR RIGHTS

WHAT OLDER PEOPLE SAY ABOUT THE NORMATIVE ELEMENTS OF THEIR RIGHT TO AUTONOMY AND INDEPENDENCE

TANZANIA



Older people in Tanzania value their autonomy and independence highly and want to see their right to this officially recognised by their government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 98 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



98 in total:
51 women
47 men



60% urban
40% rural



39% with
disabilities

Deciding where and with whom to live

Eighty-six per cent of participants said having the freedom to decide where and with whom to live was very important or important. This was important for their 'self-confidence'. They could 'control their life' and people would 'respect their decisions'.

'It means nobody can force me out of the place where I live.'
70-year-old woman

Making decisions about what matters in life

Ninety-three per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. It meant 'respect and dignity'. It meant being 'responsible' and 'ready to face the outcome' without 'blaming anyone' and with 'less regret' if the outcome is 'bad'.

'Important things for me cannot be decided by another person. Because what is important to me may not be important to him or her.'
80-year-old woman

Autonomy and independence in everyday activities and participation in society

Ninety-four per cent said it was very important or important to carry out everyday activities based on their own will and preferences. This made them feel 'liberated' and 'respected in society'. They could 'plan their activities' and 'do things effectively'.

'Because I know what is good for me.'
69-year-old man

Deciding about care and support services

Ninety per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'My freedom to decide support services means a lot. These support services concern me, so I'm happy to decide which support services are easily available and suit my situation.'
64-year-old man

Supported decision-making

Ninety-four per cent said it was very important or important to have access to support for making decisions about their care and support.

Ninety-seven per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Ninety-six per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Ninety-five per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. This would give them 'hope for the future' that they would be 'cared for and respected.' It was 'the right of every person, young or old'.

'[This] care is for my own life. I must have the right to freely choose.'
71-year-old woman

Overall response by gender

Women and men value their autonomy and independence almost equally highly. On average, 91 per cent of women and 95 per cent of men said it was very important or important to them.¹

Official recognition of rights by the government or the United Nations

Ninety-three per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.²

Recognition would enable them 'to claim their rights'. It would make services 'affordable' and 'available to all'. Recognition was important to 'increase awareness', 'protect' rights and make them 'real' and 'effective'.

'This recognition by both the government and the United Nations will help to extend the right to autonomy to all older people at all levels, even at village level.'
60-year-old man



Ben Small/HelpAge International



Kate Holt/Age International

1. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
2. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by The Good Samaritan Social Service Trust (GSSST)

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WHAT OLDER PEOPLE SAY ABOUT THE NORMATIVE ELEMENTS OF THEIR RIGHT TO AUTONOMY AND INDEPENDENCE

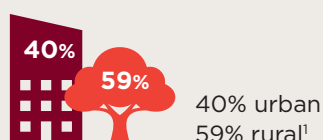
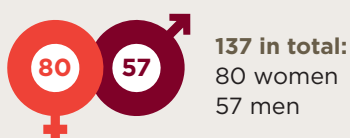
UGANDA



Older people in Uganda value their autonomy and independence highly and want to see their right to this officially recognised by the government or the United Nations.

This is the main finding of a consultation held from December 2018 – January 2019 with 137 older people. Participants were asked what they thought about different aspects of autonomy and independence. The findings presented here aim to capture their views. They are not intended to be representative of the population of older people as a whole.

ABOUT THE PARTICIPANTS



Deciding where and with whom to live

Ninety-three per cent of participants said having the freedom to decide where and with whom to live was very important or important. It was important for 'exercising their rights as an older person'. It was part of their 'freedom of speech, participation and decision-making'. It reduced 'stress' and built 'confidence'.

'I feel liberated, empowered and respected.'
71-year-old woman

Making decisions about what matters in life

Ninety-eight per cent said having the freedom to make decisions based on their own will and preferences about the things that mattered to them was very important or important. This made them feel 'loved', 'popular', 'valued' and 'important' in their communities. They felt 'excited' and 'motivated to work for themselves'.

'Because I'm a person with disabilities, I will feel included.'
72-year-old man

Autonomy and independence in everyday activities and participation in society

Ninety-one per cent said it was very important or important to carry out everyday activities based on their own will and preferences. This gave them 'authority over their life' and 'self-satisfaction'. It made them feel 'respected'. They could do these activities 'without limitation'.

'[It means] having liberty to undertake personal development without interference.'
62-year-old woman

Deciding about care and support services

Ninety-six per cent said it was very important or important to make their own decisions about their care and support, including planning ahead for future support.

'It means I have a choice to accept what I want and refuse what I do not want.'
90-year-old woman

Supported decision-making

Ninety-three per cent said it was very important or important to have access to support for making decisions about their care and support.

Ninety-six per cent said it was very important or important to have a trusted person or persons to support them in decision-making about their care and support.

Ninety-two per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

Deciding about palliative care

Ninety per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. This would enable them to 'participate' and 'choose the right care options', and make sure they were 'not given the wrong treatment'. It would reduce their 'stress', knowing they would 'receive trusted care'.

'Because my pain will be reduced, I'll have a dignified end to my life.'
63-year-old man

Overall response by gender

Women and men value their autonomy and independence equally highly. On average, 94 per cent of women and 93 per cent of men said it was very important or important to them.²

Official recognition of rights by the government or the United Nations

Ninety-four per cent said it was very important or important that their government or the United Nations officially recognise their right to autonomy and independence.³

Recognition, they said, was important to 'provide guidance on older people's rights', 'promote' them and ensure they were 'observed'. They could 'plan' and feel 'empowered'. They would be provided 'with the right support in the future' 'at community level'. Recognition would increase understanding of their right, and their 'will and desire would be observed'.

'National and international laws give people the right, and the state has an obligation to respect a person's choice.'
71-year-old woman



Ben Small/HelpAge International



Ben Small/HelpAge International

1. 1% answered 'Other'.
2. Average based on responses to a number of questions about the level of importance attached to normative elements of the right to autonomy and independence.
3. Average based on responses to a number of questions about recognition of the normative elements of the right to autonomy and independence.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by Uganda Reach the Aged Association (URAA)

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