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

**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 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’.

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

**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

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.

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

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 Resource Integration Centre (RIC)

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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**

**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

**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
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

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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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.

### 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 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

‘Otherwise it would be like being a caged bird or animal.’

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

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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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.

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 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

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.

**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.

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

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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.

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

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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.

**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 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*

**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

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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.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by the Center for Community Advancement and Family Empowerment (CECAFE)

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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.

**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 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

**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

‘They should know that even in a [residential care] home we must have the right to autonomy.’

90-year-old woman

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**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.

**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.

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’.

‘To die peacefully, being conscious I made the choice.’

72-year-old man

‘They should know that even in a [residential care] home we must have the right to autonomy.’

90-year-old woman

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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.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by Droits Humains Ocean Indien (DIS-MOI)

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[www.rightsofolderpeople.org](http://www.rightsofolderpeople.org)
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.

**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 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

100 in total: 67 women 33 men

90% urban 5% rural

67% with disabilities

109 years

41 countries

46% years

46%

48% 50%
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.

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.

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

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.

This consultation was funded by Svenska Postkod Stiftelsen (Swedish Postcode Foundation) and conducted by Ageing Nepal
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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.

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 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

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

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\(^1\) 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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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.

**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 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

**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

**ABOUT THE PARTICIPANTS**

98 in total:
- 51 women
- 47 men

60% urban
- 40% rural
- 39% with disabilities
**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

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**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

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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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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.

**Our voices, our rights**

**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.

**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

**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

**About the participants**

137 in total: 80 women, 57 men

40% urban, 59% rural

48% with disabilities

46% with disabilities
**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*

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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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