Loneliness call for evidence

Introduction

The Loneliness Strategy is Government's first step in tackling the long-term challenge of loneliness. Loneliness is a complex issue that affects many different groups of people, and the evidence base on it is still developing. The strategy will be focussed on where we have the clearest opportunity for government action and further learning.

We are interested in hearing from people and organisations with experience of working to reduce loneliness.

If you have any difficulties with this survey, please email us at loneliness@culture.gov.uk.

Completing the survey

Please return the completed survey to us either by email to loneliness@culture.gov.uk or post to:

Loneliness team
Office for Civil Society
DCMS
100 Parliament Street
London
SW1A 2BQ

We encourage everyone to consider all questions in this survey, but we understand that there will be questions which may be more relevant to you, or your organisation. You can choose to respond to as many questions as you like.

This call for evidence will close at **10am on Friday 20th July 2018**. Responses received after this date and time will not be analysed.

Disclosure of responses

The Department for Digital, Culture, Media and Sport (DCMS) controls the information you provide in your answers. Information is being collected and processed by DCMS, with your consent, for research purposes to inform the development of the Loneliness Strategy. All information will be processed in compliance with the Data Protection Act 2018 and General Data Protection Regulation and used to develop the Loneliness Strategy.

In developing the Loneliness Strategy, DCMS may publish findings from the research. If we do so, we will ensure that neither you nor the organisation you represent are identifiable, and any responses used to illustrate findings are anonymised. The only third party who we will share your information with is Qualtrics, who will be processing the survey on behalf of DCMS. Your information will not be shared with any other third parties. It will be retained for 2 years for analysis and reporting after which it will be destroyed. DCMS will not disclose any information you provide unless required to do so in accordance with access to information regimes (these are primarily the Freedom of Information Act 2000, the Data Protection Act 2018 and the Environmental Information Regulations 2004).

DCMS will be collecting partial responses to the survey. If, during completion of the survey you decide to withdraw your response, you will need to return to this Disclosure of Responses page by using the ‘Back’ button, and select ‘No’ from the options below.

Under the current Data Protection Act 2018 and the GDPR regime, you have certain rights to access your personal data and have it corrected or erased, and you can withdraw your consent to us processing your personal data at any time. However, once you have submitted your response to the survey you will not be able to withdraw your other answers from the analysis stage (i.e. it is only your personal data that you can withdraw at this stage, not your other answers).

If you need any further information please contact us: dcmsdataprotection@culture.gov.uk

You have the right to lodge a complaint with the independent Information Commissioner (ICO) if you think we are not handling your data fairly or in accordance with the law. You can contact the ICO athttps://ico.org.uk/, or telephone 0303 123 1113. ICO, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.

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Please confirm below that you have read and understood this statement and agree with its terms.

I have read and understood the disclosure of responses statement and I agree with its terms. (Select one)

- [✓ Yes]
- No

We may wish to contact you to discuss your responses in more detail. **If you are happy to be contacted, please provide your details below.** If not, please move on to the next question.

- Name: Lyndon Ashmore
- Email address: lyndon.ashmore@togetherforshortlives.org.uk
- Telephone number: 0117 989 7866

Are you responding as an individual or on behalf of an organisation? (Select one)

- Individual
- [✓ Organisation]

If you are responding on behalf of an organisation, which of the following options best describes it? (Select all that apply)

- Voluntary organisation (local)
- Business (local)
- Voluntary organisation (national)
- Business (national)
- Funder
- Public sector service provider
- [✓ Other (please specify):] National children's palliative care charity

What is the name of the organisation you are responding on behalf of?
Together for Short Lives

Are you aged 16 or over? (Select one)

- No, I am 15 years or younger
- [✓ Yes, I am 16 years or over]

If you are aged under 16, you cannot take part in this survey as we do not have consent from your parents/guardians. If you have any questions about loneliness work in government please feel free to email the team at loneliness@culture.gov.uk.

We believe that the strategy should include both some policies that reduce the risk of loneliness across all groups in society, and some that focus on reducing the risk at specific trigger points for key groups highlighted by existing analysis: young people (aged 16 to 24); people in poor health; carers; unemployed people; and bereaved people.

Do you or your organisation have experience of working on issues around loneliness with any of the following people? If not, we would still like to hear from you. (Select all that apply.)

- Young people (up to the age of 25)
- People in poor health
- Carers
- Unemployed people
- Bereaved people
- Other group (please specify)____

Do you or your organisation have experience of working on any of the following areas? If not, we would still like to hear from you. (Select all that apply.)

- Improving infrastructure that supports social relationships (eg, transport, community spaces, the physical environment)
- Building a culture that strengthens social relationships (eg, reducing stigma, building resilience)
- Institutional and organisational changes that support social relationships (eg, health and social care services, employers)
- Other (please specify) ____

We’re keen to understand the different ways that loneliness is currently being tackled, what works best and for whom.

Thinking about your experience with tackling loneliness, please tell us about any projects or initiatives you have found particularly effective and why you think this is.

1. Together for Short Lives is the UK charity for children’s palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children’s palliative care sector - so that no family is left behind.

2. There are over 49,000 babies, children and young people with life-limiting or life-threatening conditions across the UK, and the number is rising. Most of these children have complex health conditions and need constant support and care 24 hours a day.

3. Families provide most of their child’s care at home themselves, which can be exhausting. One parent may have to give up work to care for their child at home, and may face financial hardship on top of the emotional impact of knowing their child will die young. Families need regular breaks and support to make this sustainable, as well as access to 24/7 care when their child is at end of life.

4. Research carried out by Together for Short Lives in March 2018 found that 84% of families caring for a child with a life-limiting or life-threatening condition say they have felt isolated and alone since their child’s diagnosis.

5. The research also revealed:
    - 90% said their relationship, social life and interactions with friends had been adversely impacted since their child’s diagnosis.
    - 74% said the same for their relationship with their partner.
    - 87% said the same for their relationship with their immediate family.
    - For bereaved families, over 50% said their relationships with family and friends had been adversely impacted by their child’s death.

6. Families of children with life-limiting conditions face a number of challenges that mean they are vulnerable to becoming isolated and lonely. Together for Short Lives found that common reasons for becoming isolated include feelings of social exclusion and the sheer exhaustion of caring for a seriously ill child. Other families talked about how hard it is to engage with everyday social conversations or talk about anything trivial when your life revolves around caring for a seriously ill child.

7. Respondents cited access to a community of families experiencing similar challenges as being a hugely beneficial resource. As one respondent said: “I feel like I can only share my true thoughts and feelings with parents who have had a child with a similar condition. I’m part of a private Facebook group run by Together for Short Lives, and the people there lend an empathetic ear and a shoulder to cry on.”

8. Children with life-limiting conditions – and their families – also rely on frequent short breaks for respite to enable them to relieve this stress, spend time as a family and do the things that other families do.

9. When caring for a child with a life-limiting condition, 64% of mothers and 24% of fathers will need to give up work and this, combined with the extra costs of caring for a seriously ill child, means that many families may live in poverty. This cuts families off from the communities they may have previously been a part of.

10. Research conducted by Julia's House Children's Hospice and Bournemouth University found that 74% of parents rated short breaks provided by children's hospices as having a direct, positive effect on their relationship with a partner, giving them rare time together as a couple. Others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family.

11. However, as Together for Short Lives own freedom of information (FOI) requests have found, too many clinical commissioning groups (CCGs) and local authorities in England are failing to plan and fund short breaks. 21% of local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so.

12. A government-commissioned review of funding arrangements for palliative carev published in 2011 recognises that "short breaks which provide respite for the carers and families of children requiring palliative care should be funded by local authorities and the NHS under their respective legal short breaks duties."

13. Together for Short Lives would like the UK government to work with us to issue joint guidance from the secretaries of state for health and education to NHS clinical commissioning groups (CCGs), sustainability and transformation partnerships (STPs) and local authorities. This should remind them that they are all responsible for planning and funding short breaks for these children in their local areas.

14. Together for Short Lives is a member of The Disabled Children's Partnership (DCP). DCP is calling on the government to review the way in which short breaks are provided for disabled children and their families to identify and address national, regional and local funding gaps.

15. Respondents to Together for Short Lives' March survey also cited a lack of access to adequate transport as being a severe obstacle in their lives. It prevents options to socialise and visit family, friends or services that could help to alleviate isolation and loneliness.

16. Children with life-limiting and life-threatening conditions often depend on ventilators, large equipment or other types of technology to stay alive. This equipment is big and heavy. Some babies and young children have permanent wheelchairs and are not able to use buggies suitable for well children of the same age. These wheelchairs are heavy because of the equipment and need to be fixed to a vehicle.

17. Together for Short Lives are delighted that, following an announcement by Rt Hon Esther Mcvey MP, Motability is now piloting a scheme to help children under the age of three who are not eligible for the mobility component of child disability living allowance but who rely on bulky medical equipment. The scheme has the potential to help up to 1,800 families access the specialist vehicles they need to leave home or hospital.

18. Together for Short Lives will continue to work with the Department for Work and Pensions, Family Fund and Motability to understand the findings of this pilot. For the reasons set out above, we would like these specialist vehicles – or an equivalent mobility payment to those families who do not drive – to be made available to all 2,768 children in the UK under the age of three who depend on bulky medical equipment. This would help to alleviate the isolation that these families experience.

19. Children's hospices provide vital services and support within a safe, community setting. These hospices can act as a hub, allowing families in similar situations to come together and share the practical and emotional support that they need in these challenging circumstances. Some of these hospices can also provide clinical care and overnight stays, providing crucial access to short breaks.

20. Despite their amazing work – and the pressure they take off the NHS – children's hospices do not receive enough money from the state. The funding they do receive is patchy and unsustainable. Together for Short Lives considers it pressing and urgent that the overall amount of funding available through the children's hospice grant reflects the increase in demand, costs and complexity of care needed by children and young people with life-limiting or life-threatening conditions.

21. Together for Short Lives recommends that the grant is increased in value to £25 million per year. We base this on a 14% contribution to the current cost of the clinical care provided by children's hospices, which is equal to the contribution originally made by the Department of Health when the grant was first awarded in 2006/07. The uplift also recognises any additional costs in developing reporting mechanisms and new services to meet growing demand.

22. Adequate funding for children's hospices would not only enable them to provide crucial short breaks for respite care, but would also mean they are able to reach more children with life-limiting conditions and their families and help tackle the loneliness that these families so often experience.

We also want to know what has been tried and hasn’t worked, or hasn’t worked in a particular context.

Thinking of any projects or initiatives that you feel have not been effective, why do you think this is and are there any ways you feel these could be improved?

1. NA

We want to gain a deeper understanding of any difficulties organisations face in measuring and assessing the impact of their work on loneliness, to assess whether we can provide extra guidance and support.

What are the main challenges you encounter when assessing the impact of your work on loneliness?

1. Together for Short Lives’ Loneliness Report was constructed through conversations and surveys with our members. Isolated families are, by definition, challenging to reach. This means that, while we are able to build an idea of some of the challenges faced by families, we can assume that issues of loneliness are more widespread than the initial results indicate.

2. Together for Short Lives would welcome government funding to help us reach isolated families caring for children with life-limiting conditions and identify the ways in which we can connect them with other families and tackle the loneliness they experience.

We plan to develop a cross-government strategy that combines some policies that reduce the risk of loneliness across society and some that focus on reducing the risk at specific trigger points.

Do you have any comments or suggestions on our proposed approach?

1. Together for Short Lives welcomes this proposal. Children with life-limiting conditions and their families often have to engage with up to 30 different professionals and provider organisations spanning health, social care, education, housing, welfare and leisure services. It is crucial that these services joined-up around families to provide the support pathways that these families require.

2. There are a number of potential loneliness trigger points throughout the life of these children and their families. These could include the moment of birth or diagnosis; the transition from curative to palliative care; or, of course, following the death of a child. It is crucial that care pathways are established to meet the needs of families at these specific points and prevent isolation.

3. CCGs, local authorities and other agencies have a crucial part to play in making sure children with life-limiting conditions and their families get access the lifeline palliative care they need. Sadly, families face a postcode lottery of support across England because of the different ways in which CCGs and local authorities commission children's palliative care.

4. The commissioning of short breaks for respite is an example of the postcode lottery faced by families trying to access services and support. More than one in five (21%) local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so.

5. We ask the UK government to work with us to issue joint guidance from the secretaries of state for health and education to NHS clinical commissioning groups (CCGs), sustainability and transformation partnerships (STPs) and local authorities. This should remind them that they are all responsible for planning and funding short breaks for these children in their local areas. The Loneliness Strategy is an ideal opportunity to issue this guidance.

Thank you for taking part.

Although we cannot respond to all contributions, all comments will be read and considered.