



HELPLINES AT THE FRONTLINE OF HEALTH AND SOCIAL CARE

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KEY MESSAGES



1. Helplines deliver person-centred and person-led care.
2. Helplines provide a trusted space.
3. The independence of helplines is valued by callers.
4. Helplines are an unseen health provider and health solution.
5. Helplines are at the frontline of service delivery and can offer the first step to further help, as well as ongoing support.
6. Helplines can reach out effectively to vulnerable, isolated communities.

1 INTRODUCTION

Helplines are positioned at the frontline of health services and play a key role in securing the wellbeing of individuals. Not all helplines are exclusive to health, but many cross cut with health issues, especially around mental health and wellbeing.

Evidence both nationally and internationally points to the value of helplines across a number of sectors and especially in outreach for groups such as black and minority ethnic communities, disabled, older and isolated people. Many are run independently by charitable organisations, as either the only service provided, or as part of a wider range of services. Others are run in-house to benefit workers or a specific client group and, increasingly, we are seeing more helplines being run by or for statutory services. Most recently, the transformation of the health and social care landscape in England has seen an increase in the number of helplines utilised as part of a statutory service, with varying degrees of success.

Helplines can offer generalised, or highly specialist support. Callers may access helplines by phone, but increasingly they can also get access through other methods such as text, instant messenger, email or Skype. A helpline might provide support to people in a local area or throughout the country. Research from 2011 suggested that helplines in the UK take 60 million different calls each year.¹

¹ State of the Sector, Telephone Helplines Association

Helplines are facing a number of challenges. Calls to helplines have increased significantly in the past year, with some helplines reporting volume increases of over 40%. Helpline providers have also reported that the complexity of the calls is increasing, with callers experiencing multiple and complex problems relating to issues including mental health, housing, debt, unemployment or substance abuse.

Health services face particular challenges when supporting an aging population, delivering localised and personalised care services and in ensuring quality of life for people with long term conditions². The flexible and user focused delivery of helpline services may enable service transformation within existing health systems.

This paper explores five key themes of helplines:

- The scope of helplines with a health focus, across condition-specific, geographic, protected characteristics and related intersections
- The reach of helplines to the most vulnerable groups, as a front line health advocacy service
- The ability of helplines to facilitate access and signposting to other services
- The relevance of helplines to strategic priorities in health and social care
- The role of volunteers in running and manning helplines

2 BEYOND PHONES: THE MODERN HELPLINE, TECHNOLOGY AND ITS USE IN HEALTH AND SOCIAL CARE.

There are thousands of helplines in the UK today, ranging from small volunteer-led projects to large, well-known charities. Since the 1970s, there has been an increase in phone use and telecommunication developments. In response to changes in how people choose to access support, helpline platforms have shifted away from traditional telephone lines. Research carried out with university students by Nightline, a helpline for students, suggested that potential helplines users were now as likely to seek support via email or online chat as they were via telephone.³ 18% of UK households no longer have a fixed landline telephone in their home.⁴

Helplines have recognised these shifts and have adapted. A number of helplines now offer support through text messages, email and online channels. This approach enables the caller or service user to interact through the medium that they are most comfortable with.

² A mandate from the Government to NHS England: April 2014 to March 2015

³ <http://www.nightline.ac.uk/news/press-releases/digital-age-presents-new-challenges-to-helplines>

⁴ Reference available, EU household survey

Helplines actively allow callers to choose the method that most suits them when initiating contact, easing callers into discussions on challenging and emotional problems.

Helplines are also adept at encouraging callers to channel shift to more effective methods. This can be seen where helpline users initially send a text to a helpline service. Analysis of the Helplines Sector conducted in 2011 showed that responding by email may be cheaper than responding by phone. One helpline reported that three quarters of their contact comes via email and suggested that email offers the user a greater privacy when using a service. Other helplines have higher levels of telephone use, even when email, text or other communication channels are available. Helpline services are driven by the people calling and helplines have shown adaptability in offering new channels in response to user demand.

Use of multiple communication channels is also seen in helplines providing support to older people living with chronic health conditions. They also use a variety of channels and have seen a steep decline in the numbers of letters received by post and a sharp increase in the number of emails that are sent to them.

3 PERSON-CENTRED CARE, TRUSTED SPACE AND CONFIDENTIALITY

Helplines offer non-judgmental, professional support to people when they need it. Helplines can offer confidential services and impartial support or advice and give vulnerable callers a safe space to discuss problems. They can be the first port of call before being signposted to another service, offering clinical or other intervention. They are able to focus on a whole systems approach to care and support. Unlike some statutory services, helplines can be accessed without a diagnosis. The helplines sector supports a number of areas of public service delivery and the interventions from helpline workers help to prevent self-harm, reduce emergency admissions and support people to access services in the most appropriate way possible.

Anonymous and confidential services have been found to offer callers a sense of security⁵ and reduce callers' fears that they may face ridicule or abuse whilst they are in a vulnerable position.⁶ This is important when people are afraid or worried about seeking help and advice on difficult and sensitive issues.

⁵ Christogiorgos, S., Vassilopoulou, V., Florou, A., Xydou, V., Douvou, M., Vgenopoulou, S., and Tsiantis, J. (2010) Telephone counselling with adolescents and countertransference phenomena: particularities and challenges. *British Journal of Guidance and Counselling*, 38 (9), pp.313-325.

⁶ Rosenbaum, A. and Calhoun, J.F. (1977) The Use of the Telephone Hotline in Crisis Intervention: a Review. *Journal of Community Psychology*, 5 (4), pp.325-339.

Having the option to remain anonymous can reduce the psychological barriers that may prevent people from seeking help⁷ and can make seeking help appear less threatening, as well as minimising the risk of the caller suffering from the stigma or loss of social status (real or perceived) that could result from accessing other mental health services⁸. Providing assurance that calls can be anonymous gives helpline users the confidence to talk about complex issues and gives users the freedom to discuss sensitive subjects. Helplines provide a space for reflective listening, providing impartial support with no wider agenda.

4 Helplines and the statutory sector

Helpline services take place outside of core NHS provision and overwhelmingly operate within the third sector though some helplines are supported through NHS commissioned service arrangements.

The Staffordshire Mental Health Helpline is funded by 2 local authorities and 3 former PCTs. There is good understanding among commissioners about the value of the service which is well-evidenced through robust ongoing evaluation. Referrals to the helpline can come through a variety of statutory partners including GPs, Community Mental Health Teams (CMHTs), Staffordshire Police and the 101 database.

There is a need for greater recognition within commissioning structures of the value of helplines. Research by the Mental Health Foundation⁹ on mental health helplines found that most of the GPs surveyed were aware of mental health helplines (73%) and over half felt they were a useful service which could prevent crises. Both GPs and CMHTs saw the potential for helplines to play a role in supporting people with mental health problems or seeking information for themselves. Callers were very positive about helplines and their services (especially out-of-hours services) and reported positive outcomes as a result of calling. However, in spite of providing a crucial source of information for people with mental health problems and their families, the research found that in some quarters awareness of the benefits of helplines was limited amongst health professionals, meaning that some people who could benefit are missing out. The researchers also found that although helplines can form a part of an overall care package and potentially help reduce the use of more expensive services, that they should not replace other services.

⁷ Latzer, Y. and Gilat, I. (2005) Help-Seeking Characteristics of Eating-Disordered Hotline Callers: Community Based Study. *Journal of Social Service Research*, 31 (4), pp.61-76.

⁸ Rosenbaum, A. and Calhoun, J.F. (1977) The Use of the Telephone Hotline in Crisis Intervention: a Review. *Journal of Community Psychology*, 5 (4), pp.325-339.

⁹ Morgan K, Chakkalackal L, and Cyhlarova E. (2012). *Life Lines Evaluation of Mental Health Helplines*. London: Mental Health Foundation

5 The cross purpose of helplines: Equalities and impact

Traditionally, helplines have identified a segment of the population, or community of people affected by a condition or situation, to whom they offer support. For example, a number of helplines categorise themselves as providing support to people with mental health challenges or to children and young people, others provide support to those experiencing bullying or specific clinical conditions. Other helplines take on a specialist or niche role, for example, specific language helplines on mental health, helplines supporting people with disabilities and people in poor health, helplines offering support to victims of abuse, helplines supporting older people and their carers, and helplines giving support on debt and consumer affairs.

Helplines therefore provide support to people facing a range of challenges and are able to focus on outreach to a particular user group especially those equality groups who need support to interact with mainstream services on face-to-face level.

The way helplines manage issues such as confidentiality, repeat calls and emotional or challenging call content will differ. Some helplines will clearly define themselves as being a befriending service, whilst others offer information or advice. Other helplines see their role as offering reflective listening, encouraging callers to explore options and identify solutions for themselves.

The different approaches that helplines take highlight some key strengths around an individualised approach to caller support, tools for helplines to manage the demands for their services and enabling helplines to offer specialised and high quality service delivery. The disadvantage is that it can be hard for callers to know which helpline is best for them, leading to challenges in managing user expectations if the caller has a different idea of the support that they would like to be receiving. This speaks to the complexity of the sector and highlights a need for more research (as was recommended in the evaluation of the Mental Health Helplines partnership 2011) to help helplines maximise their impact with service users and their ability to complement and support wider system-led health initiatives.

The diagram below illustrates the diversity within the helpline sector, both within the target audience and the way in which the service is delivered. It highlights the cross purposes of the equality and impact focus in the work helplines undertake, which provides a degree of knowledge and opportunity for service users that is unique to helplines.

The tables below detail the two approaches to the identification and approach of helplines. Each clearly intersect each other in practice.



6 PERSON CENTRED CARE DELIVERY WITHIN THE HELPLINE SECTOR



Equalities focused approach (equalities and outreach), considering the helpline's purpose. Samples of helpline focus through community segementation.

- Mental health
- Children and young people
- Older people and carers
- Disabled people and people living with chronic health conditions
- Debt and advice services
- People from black and minority ethnic communities
- Crime and victims of crime and violence
- Lesbian, gay, bisexual and transgender people

Impact focused approach (service delivery)

- Approach to confidentiality
- Provision of advice
- Approach to befriending
- Encouragement of repeat callers
- Provision of information
- Delivery of response to emotional call content
- Evaluation of service provision
- Quality

7 OUTREACH AND ACCESSIBILITY: REACHING THE MOST VULNERABLE INDIVIDUALS

It is particularly important for people with impairments, mobility problems or long-term health conditions to have direct, timely access to advice and support. For example, people with sensory, cognitive or communication impairments and people who are neuro-diverse may find traditional voice provision inaccessible. Other platforms such as email or text messaging may be more appropriate and inclusive. A choice of communication platforms helps to overcome the difficulty of explaining an impairment or health condition verbally, particularly if the call handler is not experienced in the support needs a person may require.

For people with mental health problems, improved choice of delivery can help to promote confidence in accessing services and help to address wider communication barriers and problems that people have in engaging with formal mental health service provision. One helpline told us that:

‘The people we know are deep within the service are very mistrustful and generally feel let down and unsupported. Those not yet in the service are very mistrustful of getting involved, neither group hold out much hope of help.’

Similarly, evidence from service user consultations into health and social care services support the issues above and highlight the barriers that people face when accessing services. Commonly, people say that the provision of inclusive and accessible services gives them dignity and makes them feel safe.

‘People need training to understand that disabled people are the same as everyone else and that they must be treated equally. People assume that you can’t do things for yourself and think you can’t understand. People need to ask not assume.’

(Leadership in Adult Social Care Services - Consultation with Service Users, Shaping Our Lives January 2013).



CASE STUDY

Thematic issue- helplines and loneliness

People who are lonely can die younger. An international study looked at more than 44,000 people with heart disease in a range of countries. It found that people with heart disease who live alone tend to die sooner than those sharing their home with others. Over the four years the study lasted, 7.7 per cent of participants younger than 65 who lived on their own died, compared to just 5.7 per cent of those who didn't live alone.

The Joseph Rowntree Foundation has produced some work on loneliness which identifies loneliness as being distinct from social isolation. It defines loneliness as being a mismatch in the relationships that we have, and the relationships we want to have. Loneliness describes the pain of being alone, as the opposite of solitude, where people can take pleasure from having time to one's self. Some people seek solitude, but few people actively choose to be lonely.

The work by the Joseph Rowntree Foundation looked at responses to loneliness on a community level. Through community development work they found that loneliness could be reduced and that tackling it at a neighbourhood level built personal and community confidence which in turn built resilience enabling people to be able to withstand unexpected shocks more effectively.

Helplines tend to work beyond neighbourhood levels. Some helplines offer a national or even international service. Helplines offer non-judgemental support to anyone who needs it, regardless of location. This is important because any member of society can suffer from loneliness. It is well recognised as a risk for older people. In England, 51% of all people over 75 live alone and 5 million older people say the television is their main form of company. But a survey from the Mental Health Foundation found that nearly 60% of those aged between 18 and 34 spoke of feeling lonely often or sometimes, compared with 35% of those aged over 55. Helplines can tailor their services to support people from a range of backgrounds, and offer choices in the form of communication, like texting, web chats, email or phone.

Helplines however have an enormous role to play in tackling loneliness. We can all be lonely sometimes. Without the helplines sector many vulnerable people would be even more alone.



8 Helplines as advocates and their supportive function in enabling service users to access health and other services

The transformation of health and care services in the UK has seen a growing trend towards the use of electronic systems (via the internet) to book appointments, find health and care services and access self-help information. This is problematic for those people unable to access the internet. The latest figures suggest that 7 million adults had never used the internet and of these 3.6 million approximately were disabled people. In 2011, 61% of disabled people lived in houses with internet access compared with 86% of non-disabled people. This suggests that helplines may be of particular importance to disabled people who may not be able to use the internet to access an increasing number of health and care services.

Helplines can also enable a journey towards service users accessing face-to-face care. Initial contact with a helpline service can give a caller the information or confidence that they need to engage with mainstream services. Helplines can also provide additional ongoing support as and when the caller chooses. Helplines are also affordable to their service users, with 49.8% of services provided using non-geographic numbers, of which 68.6% are freephone or free-to-caller.¹⁰ The decision to use a free to caller number or low cost number is linked to a helpline's user base and helplines try to keep their call costs as low as possible for the user to support callers with financial barriers.

Finally, it is important to consider not only how helplines might enable disabled people and service users to access services more easily, but also the accessibility of helplines. Ensuring that services are able to meet the needs of people equally is an expectation outlined in the Equality Act 2010. However, many helplines grow organically from a demand in a community and are provided by non-profit making and voluntary sector organisations. Meeting the access needs of people with sensory, physical, communication and cognitive impairments is demanding and service providers need to invest time and money to do this.

'There is a strong perception that there is a need for greater levels of consultation and engagement with service users, but that actually the opposite is occurring, particularly as the levels of funding to the voluntary sector for advocacy and engagement have been falling.'

¹⁰ Lifelines, THA



CASE STUDY

OCD Action: Next Steps Service

The Next Steps service provides support for people with Obsessive Compulsive Disorder to move towards and through treatment, complimenting health provision. The service aims to give people with OCD better understanding of treatment options, increased motivation to visit their GP and get the right diagnosis, give people support to complete treatment programmes that can have a high dropout rate and support wider wellbeing outcomes.

The project offers additional support to helpline callers who are entering into Cognitive Behavioural Therapy programmes, connecting people from first step to end of treatment, and partners them with a trained OCD Action volunteer who has first hand experience of getting treatment for OCD. Support comes through scheduled telephone conversations, which accompanies the caller through their treatment programme, reducing anxiety and helping the caller to understand what CBT will entail. A key aim of the project is to help reduce the likelihood of people dropping out of treatment, particularly as breaking cycles of obsession and compulsion is challenging.

Support is offered to helpline callers, who are looking to access treatment, and sessions formally start from where the first treatment booked and calls are made 1-2 times per week. Callers get to speak to the same volunteer, and this additional support is offered to around 50 people a year. The helpline evaluates the service through a questionnaire and information is given at the beginning of the support package about the expectations on both sides.

The project has shown success in preparing callers for CBT, through empowering patients, and giving them confidence when speaking to therapists. The majority of helpline volunteers have lived experience and are well trained with appropriate boundaries in place. Callers like that the helpline operator can empathise with the challenges that they are facing and rate the support they receive highly. The service does not offer clinical support, it gives additional support that can only be provided by people who are outside the system, and this independence is valued by people who access support.



9 The role of volunteering and peer support

Use of volunteers within the helplines sector is high. Survey work by The Helplines Association found that 3 in 4 of staff in the sector were volunteers.¹¹ Helplines can be attractive to volunteers as a way of gaining skills, or to support a cause to which they have an attachment or personal experience, indicating that there are high levels of empathic qualities within helpline service provision. Where helplines are staffed by healthcare professionals, the development of active peer users on related web forums has been observed, creating a form of informal volunteering.

Helplines also offer opportunities for people who are recovering from mental illness to volunteer or work in the sector, providing empathic and understanding services. Surveys of the sector found that three quarters of helplines engage in quality monitoring of their services, with call-listening being the most popular form of quality management, practices by just under half of all helplines surveyed.

There are, however, some challenges that come from providing a supportive and nurturing environment for people who have or have previously experienced mental health challenges. Helplines receive some highly emotional calls from people in distress or who have experienced a traumatic situation. There can be a risk from helpline operators experiencing trigger situations if they have personal experience of surviving their own traumatic situations. Helplines manage these risks through training, call supervision and staff debriefing.

Helplines are innovators in enabling people to volunteer flexibly, with some helplines providing opportunities for people to volunteer remotely from home by logging on to a virtual call centre system. People with disabilities can encounter barriers to volunteering, particularly where adaptive equipment may be needed. Increased access to support through adaptations for disabled people to be able to volunteer would be welcome.

Helpline volunteers are dedicated and have to go through robust training and supervision processes. This ensures the quality of support given to callers and protects the emotional wellbeing of helpline volunteers.

¹¹ Lifelines, THA

9 The outcomes challenge and funding

The confidential nature of helplines can present a challenge in the measurement of long-term outcomes for individual helplines, which in turn creates considerable challenges for helplines competing for funding within highly prescriptive outcomes-based funding pots.

Funders need to ensure value in the resources that they deploy. The challenge for many helplines is that measuring success is difficult when a key characteristic is that they accept anonymous calls. Without data gathering and user tracking, it may be harder to show the longer term benefits of helpline services compared to more traditional face-to-face mental health support provision. In effect, helplines do not know what happens when the call ends: other sectors can track a cohort of users more effectively and in doing so, gain a distinct competitive advantage when competing against helplines for funds.

Most helplines do, however, undertake some form of performance measurement. This can be through user satisfaction surveys, measuring the volume of calls and developing qualitative data measurement tools to better capture the success of the interaction within the call environment.

CASE STUDY

Thematic issue- helplines and suicide prevention

Suicide takes a terrible toll on human life. According to WHO's first global report on suicide prevention 800,000 people die by suicide every year, which is around one person every 40 seconds. WHO recently published their report on suicide where they also looked at the role that helplines play in supporting people who are experiencing suicidal feelings and noted the importance of helplines. They commented that helplines in the USA have been shown to be effective in engaging seriously suicidal individuals and in reducing suicide risk among callers during the call session and subsequent weeks. The study of telephone and chat helpline services in Belgium has suggested that these strategies might also be cost-effective for suicide prevention.

The WHO noted that helplines have proved to be a useful and widely implemented best practice, but concluded that, despite reducing suicide risk, the lack of evaluation means that there is no conclusive association with reducing suicide rates. Although evaluation in a helpline environment is complex, we know that in the UK, as well as elsewhere in the world, helplines play a huge role in delivering this very important work.



Helplines offer immense value, particularly in relieving pressure on other services. This is not always recognised by health commissioners and there is a need for funders and helplines to work together to explore outcomes-based on the value of the interaction within the call environment, such as the quality of advice given or the ability to support a vulnerable person to help make a decision that will have a positive impact on their life (such as reduced self-harm, or the ability of a person with a chronic health condition to have a better sense of how to manage their health). National helplines may have particular skill and expertise in supporting people with a particular condition or a particular population demographic, such as young people or people from ethnic minority groups. This is particularly helpful where there is recognised lack of engagement with local provision by these groups. Helpline services delivered across England or the UK can provide greater reach to vulnerable people and reduce the postcode approach to service provision.

There can also be challenges for donor recognition within helpline service provision. Helpline callers value anonymity and some helplines have reported concerns on whether having a statutory logo on specialist helpline provision would reduce the likelihood of receiving calls from particularly vulnerable groups. There are also challenges in sharing data with service commissioners where the caller can be identified.

There are additional challenges for small national helplines in trying to access funding through increasingly localised funding structures. There is a need for a greater use of targeted strategic national funds in relation to helpline provision and for better support for helplines to develop more effective tools to measure the value of service provision within the call environment.

10 Conclusion

Helplines enable people to seek support, which can promote further help seeking behaviour. The services provided can be specialist, with detailed knowledge of particular health conditions or problems that people may be encountering, but they are not always about specialist services. Many provide emotional support, and are well-placed to provide a non-stigmatising service, as they give a high degree of control over disclosure, offering the user confidentiality and, in some cases, anonymity.

Helplines can be accessed by the user on their own terms, in a space that is comfortable, and increasingly, though the user's preferred method of communication as many helplines offer text, email and Skype services in addition to voice channels.



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