Choice making pathways in social care and support

Research report

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Executive summary

Findings

- Family and friends were identified as the most common source of information about care and support options, followed by organisations such as charities and advocacy organisations.
- Information (or lack of) was identified as a key barrier for people in accessing the care and support services they wanted.
- Information tended to be provided verbally, with a small number of respondents reporting receiving printed information or accessing information online.
- The information people received was not generally felt to be useful – suggestions for improving its usefulness included ensuring information covers people's needs as they evolve over time and producing information in different formats.
- Aside from information, the other factors influencing people's choice about what care and support to access included availability of care and support services; cost; and who runs the services.
- Key barriers identified to accessing care and support services aside from information were cost, eligibility, and difficulty in understanding funding processes and social care systems. Overall, respondents felt that they did not have a range of choices open to them.

Further questions and recommendations

- Questions for further research include:
  - Do people choose informal/unpaid care and support provision or do they use such provision for other reasons?
  - What is the impact of welfare reforms on unpaid carers and how this might affect the drive towards a greater emphasis on informal, community/home-based care and support provision?
- Recommendations include:
  - Information provision should be significantly improved, and clear strategies for information dissemination developed which enable the provision of comprehensive, flexible and accessible information which meets the needs and preferences of different groups.
  - Access to advice and guidance, particularly from peer support networks, should be improved to help people make choices from the information they receive
  - Questions of affordability for those ineligible for state-funded care should be addressed, and awareness raised of personal budgets.
  - Consideration should be given as to how to balance local authorities' emphasis on approved providers with individuals' rights to choose what kinds of care and support they receive.

I.   Background to the study

1.1   Policy context

The recent Care Act (2014) was intended to increase the amount of control people and their carers have over their care and support, giving people a choice in how they meet their needs for care and support and the right to challenge decisions make about their care. The ultimate aim was to "*improve people's independence and well-being*". Under the Care Act, local authorities have responsibilities to ensure that people "*get the information and advice they need to make good decisions about care and support*" and that they have access to "*a range of providers offering a choice of high quality appropriate services*"[1]. For people to be able to exercise their right to choose the kinds of care and support they want, it is also important for them to understand their options in terms of funding and in terms of the services and supports they can access or purchase. However, the systems of funding and provision of care and support services is complex and often confusing, and varies considerably between different localities. A wide range of different options, services, support providers and funding routes exist, and it can be difficult for people in need of care and support, or for their carers, to understand and negotiate this complex terrain. Many people fund their own care and support with very limited input from professionals, and for these people information is even more important.

1.2   Research objectives

The research was commissioned by Community Catalysts, a small social enterprise and Community Interest Company (CIC) based in Harrogate, North Yorkshire, which works to support people to get the help they need to live the life they want. This includes nurturing new community-driven ventures and enterprises with a care, support or wellbeing focus. Community Catalysts often work outside of conventional care and support provision, and look for radically imaginative solutions that work across different sectors. To achieve this, they work in partnership with community groups, local councils, health trusts, CCGs, policy makers and other voluntary and private sector organisations. The aim of the research was to enable Community Catalysts to improve their understanding of how people make choices about their care and support, and to explore the barriers they face. The ultimate goal is to identify some ways in which policy and practice could be improved to support people to access care and support which meets their needs and preferences and to inform the work of organisations like Community Catalysts. The research also identifies key questions and areas where further investigation is required.

1.3   Research Methods

Research questions were developed collaboratively between the research team and Community Catalysts, by identifying key areas for investigation. The questions explored the types of care or support which respondents accessed, the ways in

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[1] Department of Health (2015). *Care Act Factsheet.* Available online at
https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets

which they were paid for (where relevant) and the extent to which respondents felt their current provision met their individual needs and preferences. The role of key factors such as information, cost and availability of care and support provision in shaping people's choices and decisions around care and support was also explored. The study was carried out using an online survey administered through the BOS system. Hard copies and accessible versions of the questionnaires were made available. Ethical approval for the project was obtained from the University of Leeds.

Analysis of the survey data was carried out by producing frequencies and graphs for each question. Some cross tabulations were carried out where appropriate, although in many cases the sample size was too small to offer statistically significant correlations. By carrying out the analysis of the data presented here, the research team were able to produce some recommendations for policy and practice and to identify key questions for further research.

1.4   Sample

The survey was open to participants over 18 years old who were currently in need or receipt of care and support, and publicised by Community Catalysts through their existing networks of contacts, including social care and health organisations, user led groups, public sector teams and other relevant professionals . They used social media and email to publicise the survey, as well as distributing hard copies to relevant organisations. Information sheets (including accessible versions) were also circulated in hard copy and as electronic versions, and these provided an overview of the aims of the research and other information for participants. The survey and related information was also circulated online via the Volition[2] website.
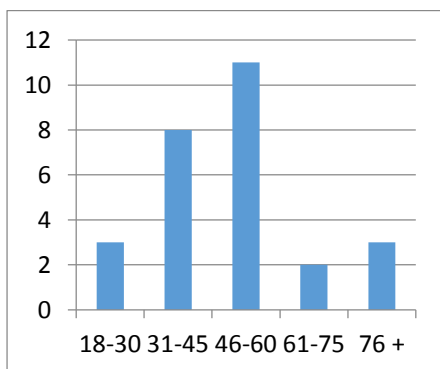
Chart 1: Participant ages

Ultimately, 30 people participated in the survey, from across different regions of the UK. Of these participants, 18 were female and 9 were male, and the majority were from White British backgrounds. The majority of participants were aged between 31 and 60 years old (Chart 1). Whilst the sample size is relatively small, the survey provides some useful insights into the choice making pathways of people in need or

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[2] Volition is a network of third sector organisations in Leeds that support people's mental health and wellbeing. They work across a wide range of settings including health and social care, housing, Arts, community development, talking therapy and carers' support.
More information on Volition at: www.volition.org.uk

receipt of care and support. The rest of this report details the key findings of the research, exploring a number of key topics.

2.   Types of care and support and sources of funding

In order to find out more about the range of care and support provision that people receive, and the take up of personal health and social care budgets, respondents were asked about the kinds of care and support they were currently receiving, and how it was funded.

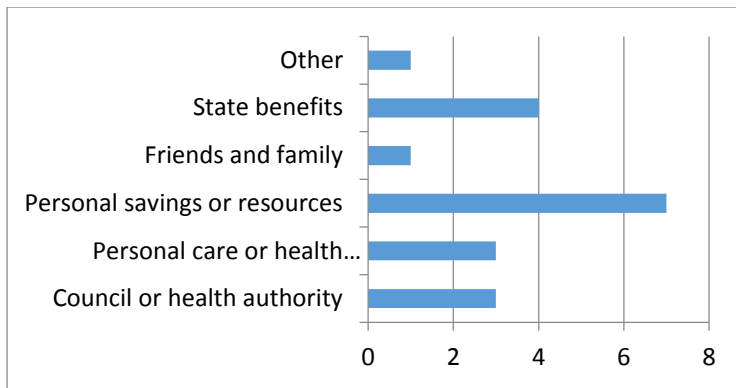### 2.1   Types of care and support received

Of the 30 respondents, 21 indicated that they were currently receiving care and support. Most were in receipt of paid or unpaid care (e.g. help with washing, dressing or preparing a meal) or unpaid help (e.g. help with household chores, personal care and shopping) at home. Figures total greater than the number of respondents because people are able to be in receipt of more than one type of care or support. Of the four respondents who indicated they received 'other' forms of support, three reported types of care and support which would be categorised as unpaid help at home, and one indicated that they were in receipt of Access to Work support in the workplace.
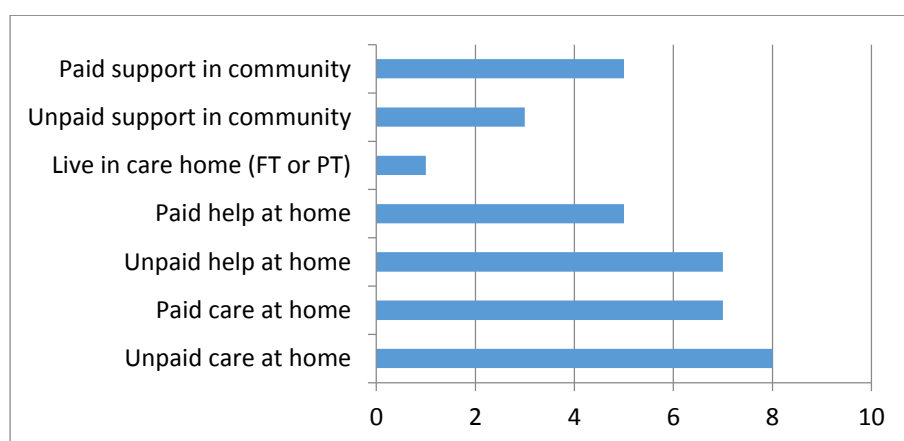
Chart 2: Types of care and support received

2.2   Funding of care and support

As already suggested, a number of respondents were in receipt of unpaid care or support. Those who did pay for their care or support were most likely to do so from their own personal savings or resources, with seven reporting this source of funding. Amongst the respondents, it was those in age groups over 60 who were most likely to pay from their own resources (probably they were not eligible for state funded care because they had resources) whilst those aged 18-30 were more likely to be using benefits to fund their care and support. Six respondents received public sector funding for their care or support and three of these took this as a personal care or health budget. One respondent indicated they used an 'other' source of funding, and this was money from a trust fund from an accident in which they were involved.

Chart 2: Sources of funding

3.   Sources and types of information

A key aim of the research was to understand from which sources people received information about their care and support options, and what types of information they received. These issues were explored in the research.

3.1   Sources and types of information

The most common source of information was family and friends, with six respondents indicating this was how they received their information. The next most common source of information was 'another organisation' (e.g. charities, organisations of disabled people and other third sector organisations). Three respondents indicated that they had received information from health professionals: one from their GP, one from a physiotherapist and another from hospital. This number is the same as the number of respondents who received information from the local council or from council workers such as social workers. There was some variation across the respondents to this survey according to age, in terms of the sources of information people received. People aged over 60 were the only respondents to indicate they had received information from their local council, and also did not report receiving any information from family or friends. In contrast, those aged 18-30 exclusively reported receiving information from friends and family. Some of the respondents indicated that they had found some difficulty in obtaining information, with one commenting that all the information they had received, they come across 'by chance'. Another stated that they "had to search for" information, whilst five respondents stated that they had received no information.

3.2   Types of information

The most common type of information received was verbal information, with nine respondents indicating this was how they received information. Five respondents reported receiving printed information such as leaflets or brochures, whilst two accessed online information. It is likely that respondents received more than one type of information. One respondent stated that they would have preferred to receive printed information "*instead of having to remember it all*". Another suggested it would be useful to receive "*all the information together in a pack (as the Care Act is*

supposed to do) instead of [getting] random scraggy bits of paper torn out of magazines and old leaflets from the hospital".

4.   Usefulness and accessibility of information

Respondents were asked about how useful and accessible the information they received was. The survey also explored how people felt that the information they received could be made more useful and/or accessible.

4.1   Usefulness

Of the 14 respondents who answered this question, only three indicated that they felt the information they received was 'very' useful, whilst six suggested it was 'fairly useful'. Almost as many (five respondents) ranked the information they received as "not at all" useful. Again, there was some variation between groups, whilst those under 30 being more likely to feel the information was "not at all" useful, and those over 60 tended to be more likely to feel the information was "very useful". People in receipt of unpaid care at home were less likely to be positive about the information they had received. When asked how information could have been made more useful, respondents had a number of different suggestions. One suggested that it would be helpful for them to have had "*information about help and support when my condition worsens - not just what I needed at the time*". Other suggestions included making information easier to find, or "*more readily accessible"* and producing information in different formats. One respondent suggested that it would have been useful for them to have been able to speak to, and obtain advice from "*someone who had been through it*".

4.2   Accessibility

Of the respondents who answered this question, eight suggested that the information they had received was accessible, whilst five felt it was not. Again, there were several suggestions of how to make information more accessible. This included providing printed as well as verbal information, as well as ensuring that printed information was available in large print versions. However, there were indications from a small number of respondents that they would have preferred 'face-to-face' or verbal information to the printed information they received. This demonstrates the highly individualised needs and preferences for information.

5.   Factors influencing decision-making about care and support

Respondents were asked about the role of information and other factors in shaping the decisions they made about what types of care and support to choose. They were also asked about the challenges and barriers they faced in finding out about or accessing different types of care and support.

5.1   Role of information

There were clear indications that information plays a central role in influencing the decisions that respondents had made about what kinds of care and support to choose. Most respondents felt that the information had been 'very' (five respondents) or 'fairly' (five respondents) important in influencing their decision. Only two stated that the information they received had been 'not very' (one respondent) or 'not at all' (one respondent) important in influencing their decision.

5.2   Other factors

As the chart below shows, the most important factor in influencing people's choices about what kinds of care and support to choose was availability. However, cost was also identified as an important factor for six respondents, whilst five stated that they were influenced by who ran the particular service. For the six respondents who stated that they were influenced by 'other' factors, one stated that they were influenced by the reputation and safeguarding standards of the organisation, and their perceptions of the safety of paid workers and whether they had been through criminal record checks. One respondent stated that they had taken advice from family and friends, whilst another spoke about how they had tried to evaluate the potential impact of the various support options on their standard of living.
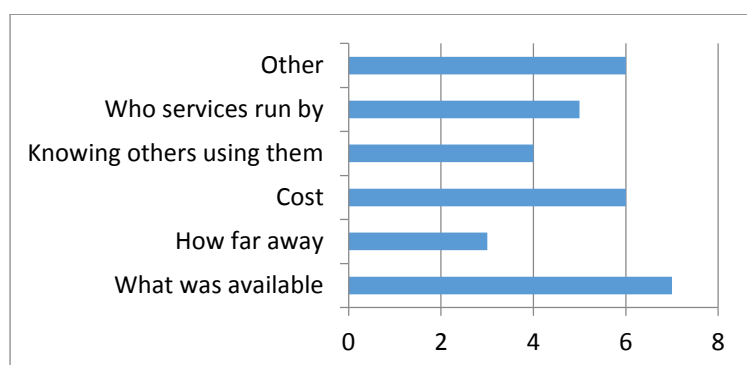

Chart 3: Other factors influencing choices

5.3   Challenges and barriers

Information was highlighted as a key potential barrier to effective decision-making, particularly in terms of people's knowledge of their options. Again, cost was raised as an important barrier for people in accessing the care and support they wanted, with specific mention being made of the fees charged by care agencies. One person suggested that they had experienced difficulties due to the fact that the service provider they wanted to use "*did not qualify under the [eligibility] criteria*". This might refer to the eligibility criteria, now set by national policy, for entitlement to state-funded care and support, which has increasingly tightened over recent years. It may also refer to the limitations placed on people using personal budgets, who are restricted to providers approved by local authorities or with whom framework contracts already exist. Both options of course have implications for policy and practice. Another respondent stated that "*not understanding the funding*" had presented a significant challenge to them in their decision making. It was also

suggested that it would be useful for people to receive advice as well as information about the types of care and support which were available, with one respondent expressing frustration with the fact that they were "*told that people 'couldn't recommend' a service"*.

6.   Attitudes to current provision and degree of choice

The final area which this research explored with respondents was their attitudes to the care or support provision that they received, and their sense of how much choice they had.

6.1   Attitudes to current provision

Attitudes to the kinds of care and support people currently received was fairly positive, with seven respondents feeling that it met their needs, and 7 that it met their needs 'to some extent'. Only two respondents said that it did not meet their needs. However, six respondents stated that they would prefer other kinds of care and support either as well as or instead of the care and support they already received, whilst seven said they would not. Responses emphasised that respondents would like to have consistency of and control over the people who support them at home. Several people also indicated that they would like access to support to engage in activities outside of the home in addition to care at home. It was also suggested that people might like to have greater access to peer support groups as a source of support and advocacy.

6.2   Options

Overall, there was a strong sense that people did not feel that they had a wide range of care and support options to choose from. Only two respondents felt that they did. In terms of age groups, over 75s were the least positive about the range of options that they could access. Five respondents were aware of options that they had not received information about, suggesting that there can be difficulty in obtaining comprehensive information that enables people to make an informed choice about how best to meet their care and support needs. Respondents who were positive about the usefulness of the information they had received were more likely to state that they had a range of options to choose from.

7.   Policy and practice relevance

This final section outlines the implications of the findings of this small study for policy and practice, and makes some recommendations for improvements.

7.1   Unpaid care and support

The continuing importance of family, friends, community initiatives and other sources of informal support is underlined by the responses to this survey. Furthermore, it is clear that family and friends also represent importance sources of information and advice about care and support options. The use of unpaid care and support suggests that a significant role remains for friends, family and acquaintances which, whilst having a number of positive outcomes, can be problematic in terms of the impact on their carers' health, relationships, paid work responsibilities and other

caring roles. It may be that factors such as cost, availability of care and support services, and a lack of knowledge about potential options might influence people's reliance on unpaid sources of care and information. In policy terms, there is a trend towards enabling people to get the help that they need from informal and community sources, particularly whilst this help is 'pre care' or 'low level'. Whilst evidence demonstrates that people tend to have a preference for informal support further investigation would be useful to help understand the reasons for this and the extent to which it is informed by the nature of formal care provision. There is also a need to understand how welfare reforms affect people in unpaid caring roles, and the implications for the fostering of informal care and support provision.

Questions for further research

- To what extent do people rely on unpaid care and support because of preference and to what extent do they do so because of a lack of alternative options?
- How do recent welfare reforms affect unpaid carers and what implications are there for fostering informal care and support provision?

7.2   Funding and the uptake of personal budgets

This research suggests that many people rely on personal savings and resources to pay for their care, and that the issue of cost is a key barrier for people in accessing the kinds of care and support that they want. This raises important issues about people's ability to access care and support. Respondents also indicated some difficulty in understanding funding processes. Whilst not everyone is eligible for state funded personal budgets, the number of people using them in this research is perhaps lower than might be expected. Other research has suggested that uptake of personal budgets – including direct payments– is limited by a lack of understanding or by a perceived lack of capacity amongst certain groups, such as those with learning disabilities , to use them. It is possible that access to personal budgets could support people eligible for state-funded care or support to exercise a greater degree of control over their care and support – as the evidence here suggests many would like – and in enabling them to meet their care and support needs in more flexible, innovative and imaginative ways. However, it is also possible that even with a greater uptake of personal budgets choices about care and support options would be limited by local authorities' focus on approved providers, as mentioned above.

Recommendations

- Raise awareness of personal budgets as an option for people eligible for state-funded social care, and/or who have a need for continuing health care
- Look at ways of supporting people to negotiate and understand funding processes
- Explore ways of informing people about low or no cost community care and support alternatives, especially for those not eligible for state-funded care
- Explore ways to address the affordability of traditional care and support services especially for people not eligible for state-funded care
- Look at ways of balancing local authorities' need to work with approved

> providers to ensure standards of cost and quality with individuals' rights to choose the care and support services they want and which meet their needs

7.3   Information

A strong theme running through this study was the importance of useful, accessible information in supporting people to make choices about how to meet their care and support needs. However, equally strong is the finding that information is frequently hard to come by, often inaccessible, and patchy rather than comprehensive. Furthermore, provision of information lacks flexibility or the capacity to meet individual needs and preferences, and even quite basic accessibility requirements, such as large print, are not being widely met. A reliance on verbal sources of information would imply that information provision is frequently ad hoc rather than strategically developed and disseminated. It is also clear that information is needed to enable people to plan ahead for their future, as well as their current, needs. Potentially, a lack of accessible, useful information might limit people's ability to find and access both informal community supports and more formal care and support services. As well as information, people need advice and guidance to help them make decisions based on the information they receive. It is likely that peer support could play an important role by enabling people to share insights based on personal experiences.

Recommendations

- Ensure that information about both formal and informal sources of care and support is made much more widely available and develop clear and coherent information provision strategies and standards
- Ensure that information provided is comprehensive, up-to-date, accessible, and available in different formats
- Develop information provision that is flexible and meets the needs and preferences of different groups, according to e.g. individual accessibility requirements, age and ethnicity
- Improve access to advice and guidance, and particularly to peer support networks that enable people to share insights and experiences

7.4   Options

Although people tended to be quite positive about the extent to which their care and support needs were being met, there were also quite a few respondents who wanted alternative or supplementary forms of care and support. The suggestions made indicate that people felt their needs could be met more effectively, or in ways they would prefer them to be met, or in ways over which they had more control. Given the other issues raised, it would seem likely that a number of factors act as barriers to people being able to access care and support that would meet people's needs and preferences more effectively.

Questions for further research

- What kinds of care and support provision would people prefer to access, and by whom would they like it to be provided?

> - How can care and support services be made more flexible and more responsive to the needs and preferences of individual users?
> - How can people be supported to understand the informal, community options available to them?

8.   Conclusion

This research provides insight into the choice-making pathways of people in need of care and support and identifies some key barriers they face in accessing the kinds of care and support provision they want. In particular, it has been demonstrated that there is a lack of clear strategy for information provision, and that information which is provided can be limited, inaccessible, inflexible or inappropriate for individual needs and preferences. Many would seem to rely on information provided by family and friends, and a significant number of people do not seem to have been provided with any information at all. These trends are worrying, and would seem to present an important barrier to realising the aims of recent legislation relating to care and health. Furthermore, there are a number of other barriers facing people in need of care and support, including cost, availability of services and understanding of the system and how it is funded. Overall, it would seem that there is a lack of 'joined-up' working to support people in making choices about, and accessing, care and support. At the same time, cuts in local authorities' funding would seem to have important implications for care and support provision, particularly as areas like Adult Social Care are increasingly facing cuts. The impact of welfare reforms on unpaid carers and cuts to funding grants for community groups including peer support groups and voluntary organisations –the most common sources of care and support to respondents in this research – is also likely to be significant. The recommendations made in this report are likely to be able to support the choice-making of people in need of care and support, and the research raises some important questions for further investigation.

For Community Catalysts the research confirms anecdotal evidence about the challenges faced by many of the community enterprises and ventures it helps to nurture including:

- Getting information about the services and supports on offer to people who need care or support and their advisers
- The limitations of personal budgets in practice rather than theory - knowing people who need care or support will have access to the funding they need to purchase services
- Communicating the fact that they offer low-cost, community rooted alternatives to more expensive formal care services