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Developmental studies for the National Adult Social Care User Experience Survey: technical report

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Introduction

This report is a supporting document for the main report on the development of the National Adult Social Care User Experience Survey (NASCUES) (Malley et al 2010). The aim of this report is to provide more detail about the methods for data collection and analysis used in the four studies and should be read in conjunction with the main report. This report is organised into four sections, covering each of the four studies.

Prior to undertaking the field work, the study was reviewed by the Social Care Research Ethics Committee. We also received support from the Association of Directors of Adult Social Services (ADASS) and gained research governance approval within each of the sites.

Study A: Understanding the impact of having help to complete the questionnaire on responses

Method

The research team interviewed people who had reported having help to complete a previous User Experience Survey (UES). All service users were interviewed in the presence of someone they knew who would (or at least could) ordinarily help them to complete the self-completion questionnaire. Interviews were conducted with users of a range of social care services. Users themselves also had a range of issues encompassing varying levels of physical and mental disability.

A total of 11 interviews of service user-helper pairs were conducted in November 2009. Participants were recruited via local authorities based in four geographic locations: London, the South East, Midlands and the North of England.

Each interview lasted between one and two hours and was (with permission) recorded onto digital audio. The interview process was an iterative one with refinement of questions. This means that after the first five interviews some provisional analysis was conducted and findings were fed back to the research team. Changes were made to questions based on these early findings, particularly where problematic terms, phrasing or any difficulty for users and their helpers to understand questions were identified. These changes were then tested in the field, with results being fed back to the research team once again. The process of amending where necessary was then repeated before continuing with fieldwork.

Recruiting participants from London and the South East proved to be particularly challenging - only one interview was conducted in the South East and none in London. An additional interview and focus group with service users (without people who would ordinarily help the user to complete the questionnaire) was therefore set up in London via the London School of Economics (LSE) user group and was conducted to test final versions of questions. One user took part in the interview and three service users took part in the focus group, taking the total number of service users who took part to 15. This additional fieldwork proved useful for testing the meaning and interpretation of questions in a group setting. Including those people that helped service users to complete questionnaires, the total number people who took part in the study was 26.

Recruiting participants

Each local authority that took part in the study was asked to contact a number of users of social care services inviting them to take part. Users who had indicated in a previous UES that they had help with completing the survey were identified. They were then asked if they would like to take part, together with the person who would normally help them.

Potential participants were initially contacted by mail by the local authority, who forwarded information on behalf of the research team. Participants were then invited to reply directly to the research team by freepost to register their interest in taking part. They were asked to sign a form consenting to be contacted by a member of the research team. Once this had been received, participants were contacted by a member of the research team and asked if they were still happy to take part and, if they agreed, a suitable time and date for the interview was arranged. Prior to the interviews taking place, each participant was asked to confirm they were still happy to take part; if they agreed they were then asked to sign a consent form. For those participants who lacked the capacity to consent, the proxy interviewee was asked to sign consent on the service user's behalf. At the end of the interview each interviewee was given a high street gift voucher to the value of £20 to thank them for taking part.

Study B: Understanding issues associated with conducting the survey in care homes

The research team interviewed care home managers and residents to improve understanding of what types of problems were likely to be encountered when carrying out a postal survey in a care home and to test the appropriateness of the proposed questionnaire for care home residents.

Identifying and recruiting participants

A selection of care homes who were interested in taking part in the survey were identified by the Care Quality Commission (CQC) and their inspectors. From this list, four care homes were chosen to take part in the study. The aim was to reflect the diversity found among care homes: therefore, homes of differing size and in different parts of the country were chosen, including London, the South East and the North of England. Moreover, the selection included not only care homes for older people but also those which catered for people with mental health problems and learning disabilities.

Care homes were initially contacted by a CQC inspector and this was followed up with a letter of invitation from PSSRU. Once care homes had agreed to take part in the study, an interview with the care home manager was organised. In addition to feeding into the findings of the study, these interviews were part of the recruitment process of residents. In consultation with care home managers, residents of care homes were invited to take part in the study. Care home residents were also chosen to reflect the differences, particularly with regard to severity of needs, among the residents of that particular home. All those who agreed to participate were given an information sheet and a consent form. In a few cases, it was decided to seek consent from a family member.

The Interviews

In November and December 2009 four interviews were carried out with care home managers. These were semi-structured interviews which asked managers about their care home and how any survey would be carried out in their home. With managers' agreement, the interviews were recorded onto digital audio (see Appendix 1, page 12 for schedule).

Sixteen interviews with care home residents were carried out between November 2009 and January 2010. A further three care home residents were recruited into the study, but in each case the interview was abandoned either just before or in the first few minutes of the interview. Reasons for this included poor health and concerns that the interview might cause the resident distress.

Because the study had recruited residents that reflected the diversity of care home residents, some residents required help from either a member of staff or a relative in order to participate in the interview. In total, six interviews were carried out with help from a member of staff or relative. Before the interview began, each participant was asked if they were still happy to take part and happy to be recorded.

The interviews themselves drew on cognitive testing (Willis 2005) in that, via a combination of probes and thinking aloud, residents were asked to share their views on the questions, how they arrived at a certain answer and what specific aspects of a question meant to them. However, because of the diversity in severity of impairments among the participants, there was some variation in how the interviews were actually carried out. Most were structured around just getting the participant to work through the survey questions and give answers. In some cases, the interviews adhered more strictly to the principles of cognitive testing, and participants were able to reflect upon their answers. In other cases, the interview was more akin to a semi- or unstructured qualitative interview where broad issues where discussed, not always with strict relevance to the questions that were being tested. This meant that there was a range in the duration of interviews: some lasted less than half an hour, others lasted nearly an hour and a half. Each resident who participated received a £20 gift voucher

Like study A, interviews were carried out in small batches, so that the findings of these interviews could be fed into any alterations to the questionnaire. This amended questionnaire was then used in subsequent interviews and the changes tested by care home residents.

Study C: Making the NASCUES accessible for people with learning disabilities

Method

Four focus groups were conducted in November 2009. A total of 23 people with learning disabilities took part (three groups involved six people with learning disabilities; one had five people). They were recruited from a variety of local day or supported employment services, and all groups were held in these venues. In two of the groups a member of staff was present to support the service users. This was very helpful, as several people had significant problems with speech and communication, and the presence of someone who knew them helped their participation. In the groups where staff were not present, individuals with communication problems were inevitably somewhat marginalised.

In general, about half the people present in each group actively participated in the task. Others were silent, acquiescent and/or struggled to understand the task.

Each group ran for approximately one hour, after which concentration and interest tended to wane. The researcher made a preliminary attempt at simplifying the survey and this material was then shown to participants. The researcher then explored with them ideas for increasing the accessibility of the content.

The amended survey questions were then piloted with 10 people with learning disabilities (also recruited from local day services) to test whether the questions were indeed understandable by a sample of people with learning disabilities. Two versions of the interview were piloted: five with a 7-point scale for the satisfaction with services questions and LD version of EQ-5D; and five with a 5-point scale for the satisfaction with services questions and the original EQ-5D. In the 10 interviews with people with LD, staff were not present to give help. The interviewer read out all the questions and possible answers, and clarified the meaning of unfamiliar terms where necessary. Participants ticked boxes by themselves, but if their verbal response did not match where they were about to tick, the interviewer again read out the answers and, in some cases, helped the person make the right match.

Audio recordings were made of both the focus groups and the pilot survey completion sessions.

Identifying and selecting participants

The research team contacted local learning disability services to recruit volunteers. Care was taken to include both men and women and adults of a wide age range, but it was not possible to ensure that participants were ethnically diverse, due to the homogeneity of the local population. The fact that people needed to give informed consent to participate (in both the focus groups and/or pilot survey completion) meant that the research included those with mild and moderate learning disabilities only, and not those with severe or profound learning disabilities.

Once potential participants were identified, they were sent accessible information sheets to enable them to decide if they wished to proceed. If they did, they were asked to sign consent forms. Then appointments were made to meet the researchers and for the focus groups to take place. Each individual was subsequently thanked by letter and, in line with good practice, all participants were paid a small sum (£20) as a token of appreciation.

Study D: Exploring the feasibility of using advocates to help people complete the NASCUES survey

There are many situations in which people may require some support to ensure that their voice is heard. The level of support required depends on the situation and the needs of the individual. In order to cover a wide range of potential needs and circumstances, there are several types of advocacy (see appendix 2, page 13). This study focuses on advocates providing citizen and peer advocacy (whether provided on a paid or voluntary basis) and their potential role in enabling people to complete the NASCUES survey. This study aims to understand the extent to which advocates could be employed to help service users complete the NASCUES questionnaire, and the impact of their involvement on responses to the survey. Two stages were necessary to explore the feasibility of involving advocates: a literature search, and interviews with local authority managers and advocacy agency managers.

Literature search

The first step was to carry out a literature search to identify any previous studies involving advocates as proxies in survey research. Three databases (Web of Science, Social Care Online and OpenSIGLE) were searched for articles relating to survey questionnaires and advocates as facilitators or proxy respondents (see appendix 3, page 14 for full search strategy). The abstracts of 207 identified sources were reviewed and 27 were found to be relevant. Of the 27 articles identified, 24 articles discussed the validity of using proxy respondents, but none of these studies involved advocates specifically. The remaining three articles described a series of projects in one local authority where advocates helped people with disabilities give their views about social care services; however, only one of these used survey methods.

The literature search identified only three articles describing projects involving advocates to enable people to participate in research, all of which were carried out by Essex County Council. It is important to note that the search strategy used will have identified only those projects that have been listed on citation databases, and there may be other unlisted examples of work where service users are helped to engage in research using the support of advocates.

The first project (Johns et al 2004) was a survey of 250 people using physical and sensory disability services. The majority of respondents (n=230) gave their views during a 15-minute structured telephone interview. The remaining 20 respondents needed more help to meet their individual communication needs. Advocates from two local advocacy organisations were trained and paid to carry out face-to-face interviews.

The second project (Johns 2004) involved 31 in-depth face-to-face interviews with service users with physical and sensory impairments. The interviews were conducted by four disabled people with physical/sensory impairments who were employed on a consultancy basis as co-researchers. The co-researchers received validated research training to enable them to fulfil this role. The third project (Baxter 2005) was a pilot study involving four advocates who interviewed 14 people with a learning disability to assess their quality of life and lifestyle satisfaction patterns. The interviews took place before and after the implementation of a new self-review process, that advocates facilitated participants to carry out independently. Improvements to quality of life and lifestyle satisfaction were found and were attributed to the empowering effects of being in control of decision-making during the review.

Interviews

Telephone interviews were conducted with seven managers in five local authorities. The five local authorities selected differed in terms of type, size and population density, allowing information on a range of circumstances to be collected. The managers were selected on the basis that they were responsible for service user surveys (see appendix 4, page 15 for interview schedule). Further telephone interviews were carried out with five advocacy agency managers across four local authority areas. The advocacy agencies were selected to ensure that a range of organisations were included, in terms of size and primary client group: for example, older people, people with learning disabilities, and people with mental health problems (see appendix 5, page 16 for interview schedule).

References

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Johns, T. (2004) *Equal Lives Evaluation Report: What difference does it make? Disabled people ask the questions. Evaluation phase 2 – a qualitative approach*, Essex County Council, Chelmsford. http://www.essexcc.gov.uk/vip8/ecc/ECCWebsite/content/binaries/documents/ELQ2-FINAL_REPORT_2004.pdf

Johns T, Miller P, Kopp K, Carter Z, Wright N (2004) Equal Lives? Disabled People Evaluate an Independent Living Strategy for Essex Social Services, *Research Policy and Planning*, 22 (2) 51-58.

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Willis, G. (2005) *Cognitive Interviewing: A tool for improving questionnaire design*, Sage, Thousand Oaks, USA.

Appendix 1: Care home manager interview schedule

1. Can you describe to me how post is given to residents and how residents letters are posted?
2. Do you have regular communication with the each of the councils that pay for your residents?
3. If a resident asked you to help them fill in a questionnaire what help would you give? Who would help? Would you suggest they ask someone who is independent from their care?
4. Is it possible that a relative/friend may help the resident answer the questionnaire? How likely is this? What about people who have no/very few visitors? Would you consider asking an advocate?
5. What would you do if a questionnaire arrived for someone who lacked the capacity to consent to research? Would you contact a representative of the person/panel of representatives? Do you have any residents for whom it would be difficult to identify a representative?

Appendix 2: Different types of advocacy

Different approaches can be taken to advocacy. Some advocates use a casework approach and build a relationship with a client (sometimes referred to as a 'partner') over time; others work on a short-term basis to resolve a particular issue. Some advocates are paid, but others are unpaid volunteers.

Types of advocacy[1]

Citizen advocacy is a one-to-one, long-term partnership between an independent 'ordinary person' and a disadvantaged 'partner'.

Collective advocacy is self advocacy by members of groups and organisations that provide mutual support, skill development and a common call for change.

Independent Mental Capacity Advocacy is required when someone is unable to make decisions for themselves because of the nature of their illness. Independent Mental Capacity Advocates (IMCAs) represent someone's best interests when major life decisions are made, such as treatment for a medical condition or a change of residence. The involvement of IMCAs is focused on life-changing decisions and is time- limited.

Legal advocacy is undertaken by a lawyer and is the most widely recognised form of advocacy.

Peer advocacy takes place where one person advocates for another who shares a common experience, difficulty or discrimination.

Professional advocacy can refer to the partial advocacy role of staff in health, social care and other settings. Alternatively, some people use the term professional advocacy to refer to the work carried out by paid advocates.

Public advocacy describes the activities of organisations that campaign on behalf of a particular group of people or collective issue.

Self advocacy essentially means speaking up for oneself to represent one's own needs, wishes and interests.

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[1] Adapted from:

Dunning, A. (2005) Information, advice and advocacy for older people: defining and developing services, Joseph Rowntree Foundation, York.

Appendix 3: Literature search strategy

Web of Science (Social Science Citation Index, Science Citation Index, Conference Proceedings Citation Index). Web of Knowledge interface. 1970-2010. Searched 13/01/10

Topic=(advocate or advocacy or proxy) AND Topic=(survey or questionnaire)
2443 results

This initial search identified too many articles to read in the time available. The Web of Science covers literature from a wide range of disciplines, meaning that a large proportion of the articles identified may not be directly relevant. Therefore, the search terms were limited to a title search only:

Title=(advocate or advocacy or proxy) AND Title=(survey or questionnaire)
58 results

The abstracts of these 58 articles were reviewed and 19 were found to be relevant.

Social Care Online 1950-2010. Searched 19/01/10

(freetext="advocate" or freetext="advocacy" or freetext="proxy") and (freetext="questionnaire" or freetext="survey")

240 results

The titles of 240 articles were reviewed and from these 139 were selected for abstract review. As Social Care Online focuses on social care and includes projects listed on the Research Register for Social Care, it was assumed that the material would be more likely to be relevant to this project. However, of the 139 articles only eight were found to be relevant, suggesting that little work has previously been carried out involving advocates to help social care service users to participate in survey research.

OpenSigle (System for Information on Grey Literature in Europe) 1950-2010. Searched 26/01/10

Keyword=((advocacy OR advocate OR proxy) AND (survey OR questionnaire))

10 results

A review of the abstracts found that none of the articles identified was relevant to this study.

Appendix 4: Local authority manager interview schedule

How feasible do you think it would be for advocates to help service users complete questionnaires?

Have you used advocacy agencies before?
  What was your experience of using agencies?

Have you used another type of organisation/service for a similar purpose?
  What was your experience of doing this?

What advocacy agencies would you use in your area?
  What is your sense of the capacity of advocacy agencies to help users in this regard?

Would there be any cost implications for the LA?

Do you have any sense of whether the situation would be similar in other LAs?

Appendix 5: Advocacy agency manager interview schedule

How feasible do you think it would be for advocates to help service users complete questionnaires?

Have you been asked by the LA or another agency to do something similar?
    What was your experience?

How much capacity would you have to help service users in this way without it impinging on your other work?

Do you feel advocates have the necessary skills or would they need training?
    Who would be best placed to conduct this?
    What would the cost implications be?

Do you have any sense of whether the situation would be similar in other advocacy agencies?