Measuring outcomes of social care

Juliette Malley and Ann Netten

Personal Social Services Research Unit, University of Kent, and London School of Economics and Political Science

Abstract

We summarise interim findings from the initial development stage of the Outcomes of Social Care for Adults (OSCA) project, which is developing a gold standard preference weighted measure of social care outcome. The project is building on previous work, including the Adult Social Care Outcome Toolkit (ASCOT) which is designed to capture information about an individual's social care-related quality of life (SCRQOL). The aim is for the measure to be applicable across as wide a range of user groups and care and support settings as possible. Analysis of datasets that have used ASCOT in previous projects identified the domains of occupation, social participation and involvement, and safety as areas for improvement. Conceptual work also identified the need to add a domain reflecting 'dignity' - the impact of the way services and support affected people's sense of personal worth. Cognitive testing with 29 service users confirmed the relevance and scope of the domains and that the final wording reflected the intended meaning. The next steps are to test the psychometric properties of the measure with a sample of service users. The measure is being proposed to be included in the planned user experience survey to cover all service user groups from 2011.

Keywords: Measurement, outcomes, social care

Introduction

Reflecting a general trend across different government departments, measuring outcomes is increasingly important at all levels of policy and practice in adult social care. Social care is rapidly developing in terms of personalisation and, consequently, potential diversification in what constitutes services and support (Department of Health, 2008, 2009*)* and is likely to continue to do so. This provides major challenges for those concerned with ongoing monitoring and evaluation of the benefits and quality of this provision. However, social care focuses on fundamental aspects of people's well-being and these do not change. Ideally, what we want are measures that reflect what the current pattern of provision is achieving, in a way that can be applied to future developments.

We are developing a measure of social care outcome that is intended to capture all domains relevant to social care interventions, have credibility in the social care community, and demonstrate good psychometric properties (be valid, reliable and sensitive to differences between individuals, interventions and changes over time). In scoring the measure, the aim is to reflect the relative importance of different aspects of outcome, ideally distinguishing any difference between service user views and those of the general population.

The work that we report on below is being undertaken as part of the Outcomes of Social Care for Adults (OSCA) project, which is building on work that has been undertaken on outcome measurement over a number of years, including, as we describe below, the evaluation Individual Budget pilot (Glendinning *et al.*, 2008). The

measure being developed is part of the Adult Social Care Outcome Toolkit (ASCOT) and is referred to as the ASCOT measure throughout. The toolkit is being developed as part of the Quality Measurement Framework (QMF) project, which is led by ONS and is developing techniques for measuring and monitoring outcome in care homes and for low-level interventions. The work has also drawn on, and fed into, national service User Experience Surveys (UES) including the planned new survey to reflect the *Putting People First* agenda.

The first phase of the OSCA project focused on development of the instrument itself and testing approaches to identifying preference weights to allow the relative importance of the different domains of outcome to be reflected. Full details and the results of the preference study are reported elsewhere (Netten *et al.*, 2009a&b). This paper summarises the findings of the work that focused on the development of the instrument.

We begin by outlining the methods employed in this initial developmental stage of the project. The concepts underlying the measure and its structure are described before summarising the results of the analysis of data from previous studies that had used earlier versions of the measure. We describe the key issues that arose when testing the wording and concepts with service users before outlining the way forward, including the proposed use of the measure in future user experience surveys.

Methods

An important first step was defining the theoretical underpinnings of the measure and ensuring that it had face validity in reflecting the objectives of social care. We drew on datasets that had used previous versions of the measure to identify psychometric properties to date and where development work was needed. We

consulted with service users and carers on what we were proposing to test and with a reference group of 11 key stakeholders including policy makers, local councils, regulators and other observers before undertaking cognitive testing of the questions and concepts with 29 service users reflecting a variety of user groups and living circumstances.

Conceptual basis of the measure

Scope

The ASCOT measure is designed to capture information about an individual's social care-related quality of life (SCRQOL). The aim is for the measure to be applicable across as wide a range of user groups and care and support settings as possible. In identifying and defining the domains (see Table 1) the aim was to ensure the measure is sensitive to outcomes of social care activities. While the original basis of the Older People's Utility Scale (OPUS), a precursor of our measure, took a top-down perspective in identifying key domains of outcome in social care, subsequent work has been concerned with extending the scope of the measure to take account of all aspects of outcome relevant to all user groups (Netten *et al.*, 2009a&b). Analysis of the literature and evidence from consultation with service users, experts and policy-makers, as well as focus group work and interviews with service users, indicated that the measure captures aspects of SCRQOL that are valued by service users (and policy-makers) (Qureshi *et al.*, 1998; Bamford *et al.*, 1999; Netten *et al.*, 2002; Harris *et al.*, 2005; Netten *et al.*, 2005; Malley *et al.*, 2006; Miller *et al.*, 2008).

In the consultation process, local council representatives and regulators were particularly concerned with the relationship between these and policy areas of outcome, such as those identified in *Our Health, Our Care, Our Say* (Department of Health, 2006), *Putting People First* (Department of

Health, 2008) and associated compliance criteria developed for regulation purposes. These observers felt the measure would be more useful if it directly related to these. While policy outcomes are helpful for policy purposes, they do not provide a good framework for measurement, covering very variable levels of generality, from broad areas such as 'quality of life' to those that can be seen as aspects of quality of life such as 'choice and control' and 'freedom from discrimination and harassment'. Rather than structuring our measure around policy objectives (that may well be reformulated over time) we think it important to clarify how our measure relates to, and might be used to, monitor progress in these areas of outcome.

We excluded specific health related domains such as pain from our measure, as something best measured by other indicators (for example EQ-5D). However, by meeting needs that otherwise would result in poor health (indicated by high level needs in each of our domains), we would expect social care to result in improved health.

In addition to domains of outcome used in previous versions of ASCOT, Qureshi and colleagues (1998) also identified 'process outcomes' associated with the way that care is delivered. Many aspects of process, such as reliability of services, we would expect to see reflected in our outcome domains, such as control. However, we added a dignity domain to reflect those aspects of the process which, as care and support become part of someone's life, reflect the effect of this on their quality of life. This is defined in terms of the impact of the care process on how an individual feels about him- or herself (self-esteem).

Table 1 Domains of outcome

Aspects of quality of life	Definition
Accommodation cleanliness and comfort	The service user feels their home environment, including all the rooms, is clean and comfortable.
Control over daily life	The service user can choose what to do and when to do it, having control over his/her daily life and activities.
Dignity	The negative and positive psychological impact of support and care on the service user's personal sense of significance.
Food and nutrition	The service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food and drink which he/she enjoys at regular and timely intervals.
Occupation	The service user is sufficiently occupied in a range of meaningful activities whether it be formal employment, unpaid work, caring for others or leisure activities.
Personal cleanliness and comfort	The service user feels he/she is personally clean and comfortable and looks presentable or, at best, is dressed and groomed in a way that reflects his/her personal preferences.
Safety	The service user feels safe and secure. This means being free from fear of abuse, falling or other physical harm and fear of being attacked or robbed.
Social participation and involvement	The service user is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends and family, and feeling involved or part of a community should this be important to the service user.

Capabilities and functioning

For people with impairments, quality of life is often limited by their ability to pursue the different aspects of SCRQOL, often due to environmental and, sometimes, financial barriers. Aligning itself with the social model of disability which foregrounds the contextual barriers over individual impairments, the focus of much policy has been on broadening opportunities for people with disabilities and developing 'independence', 'choice' and 'control' (Cabinet Office, 2005; Department of Health, 2005; Department of Health, 2006). It is argued that it is this flexibility and freedom that people want most and value from services.

This focus on choice and control is consistent with the capabilities framework, put forward by Sen (see e.g. Sen, 1985) as an alternative to standard welfare economics (Burchardt, 2004). Sen argues that 'utility' is not the sole object of value; it is rather 'capability', understood as the substantive opportunities an individual has to be, or to do, a range of things, that is the object of value. Capabilities are contrasted to functionings, which are understood to be states of being (for example being well-fed or being safe) or activities (for example, shopping). Most health outcome measures, for example the EQ-5D (EuroQol Group, 1990), capture functionings and ask people to value these functioning states. However, if it is capabilities and not functionings that are valued then each domain should be designed to capture the individual's capability rather than her or his functioning state.

The distinction between capabilities and functionings is of central importance to the development of a measure of social care outcome. On the one hand, evidence from user movements and research implies that it is opportunity or capability that is valued. But, from another perspective, functionings are important. For some aspects of SCRQOL, it could be argued that a low level of functioning is indicative of need, whether a person recognises that need or otherwise. For example, someone who is anorexic may choose to have poor nutritional intake but, as a society, we deem the level of functioning poor enough to require some form of intervention. Similar issues exist for people with disabilities as they may adapt to their circumstances (for example, in a poor quality care home), adjust their expectations and judge their opportunities within an aspect of their life to be quite good. However, an external observer might identify the potential for much better opportunities for that individual in another care environment. If it is the case that, for each SCRQOL aspect of people's lives, there is a level of functioning that we as a society judge to be unacceptable our measure should reflect this.

Earlier versions of the measure used three levels of need in each domain and language that focused on functioning. In order to ensure the measure could reflect the increased policy emphasis on capabilities, an additional level has been included for each domain in our current measure, with the domains phrased in the language of capabilities at the high quality of life end of the spectrum and in terms of functionings when reflecting low quality of life.

Attribution

A major problem in measuring outcomes in social care is reflecting the full value of what has been provided. Most social care is for people with long-term conditions where 'before' and 'after' only reflect the marginal impact of an intervention. For those where the underlying health state deteriorates, a before and after measure might reflect no change, where in practice there has been considerable increase over the period in the contribution of the intervention to people's well being. It is also difficult to distinguish the effect of changes that are attributable to interventions from other factors, such as life

events in the absence of specific research designs such as randomised control trials. People who use services and support know themselves the contribution that services make and their likely (or occasionally actual) situation in the absence of those services. In order to reflect this in face-to-face interviews, in addition to a question asking about a person's current status within each domain, there is also a 'hypothetical' question that asks people to rate what their quality of life would be like in the absence of services, or their 'expected' needs of SCRQOL (see Box 1). These questions can be combined with those asking about current status to provide a measure of the contribution of social care services to SCRQOL.

This approach provides a basis for measuring 'maintenance' outcomes (Qureshi *et al.*, 1998), associated with long-term care which, despite increased policy emphasis on prevention and enablement, continue to comprise the bulk of social care activity. It is important that we do also identify the outcomes of prevention and enablement interventions, however. In this approach, changes in the 'expected' needs of SCRQOL would best reflect this. These 'expected' needs are highly correlated with health and associated indicators such as abilities in activities of daily living (ADL) measures, so changes in these could be used as a proxy measure in some circumstances.

Evidence from previous use of the measure

Previous versions of the ASCOT measure have been used in a number of studies, most notably in the Individual Budgets evaluation (IBSEN) where it successfully identified the impact of personalisation both in the overall measure and in the domain of control (Glendinning *et al.*, 2008). Versions have also been used in User Experience Surveys (UES) for younger adults and older home care service users. These datasets allowed an analysis of how the measure has behaved

when used across a variety of service user groups in the past and where there was room for improvement. Netten *et al.* (2009a) describe how the measure has developed over time. Here we summarise the results of an analysis of the psychometric properties of the items and measure in the IBSEN (which was conducted through interview and included the hypothetical questions) and younger adults (YA) UES datasets (which were based on a self-completion questionnaire).

Item response rates

In both datasets a number of the items had non-response rates that were greater than 5%, suggesting room for improvement in the wording of these items. In particular, the employment and occupation item was missed out by a number of respondents in both the YA UES and IBSEN datasets, suggesting that there was some element of the question that respondents did not like, and the social participation and involvement item was omitted for a number of respondents in the IBSEN questionnaire suggesting some problem with the wording. In these datasets a separate question was included about role support, which was intended to identify the degree to which services supported people in their caring responsibilities for others. This was judged as not applicable by such a large proportion of people that it was excluded from subsequent analysis. The occupation domain now covers this aspect of quality of life.

In general, the items were more problematic for the mental health and learning disabled client groups in the IBSEN study, which may reflect the fact that, at this point, cognitive testing on the questions used had been undertaken only with the physically and sensorily impaired people. Some testing had also been undertaken with the older people, but not of the employment and occupation and social participation and involvement domains. Not surprisingly,

these items tended to be answered poorly by older people.

Scalability

Using a variety of approaches, one scale was extracted indicating that the questions were reflecting a single construct. The analysis suggested that, in these datasets, the items formed a weak scale but performed well in terms of appearing to consistently reflect an underlying latent construct. Since current SCRQOL is affected by a number of factors, we would not expect a strong scale to emerge. In the IBSEN dataset the safety and control items fell below the threshold for scale acceptance, but when proxy respondents were removed from the dataset these items moved above the threshold. Further analysis indicated that proxy respondents may be answering questions differently from service users, which has consequences for comparability of answers from proxy and non-proxy respondents.

Reliability

In all analyses, the estimates for the reliability of the scale were greater than 0.7. This indicated that the scale had good reliability. A coefficient of reliability greater than 0.8 is desirable for a widely-used scale and 0.7 is considered to be adequate. Given that there are multiple factors influencing current needs in each domain, the level of reliability achieved seems good.

Discrimination

Responses to the current status items were clustered towards the 'all needs met' levels. This means that these versions of the scale (based more closely on needs and functionings) were not very good at discriminating between people who score highly on the scale. The clustering of the responses at the high end of the current status scale is probably the (desirable) result of the effect of services. As we would

expect, the responses to the hypothetical status scale had a much better distribution and were more evenly spread throughout the length of the scale.

The instrument

The evidence from these analyses, conceptual development and results of the consultation with stakeholders and service users and carers (Netten *et al.*, 2009b) fed into the draft instrument that was then cognitively tested with 29 service users from a variety of user groups. In addition to testing the questions, the interviews tested out the preference elicitation techniques, which drew out important insights both into what was important to people and these aspects of their lives.

Question wording

The term *control over daily life* was understood by the people we interviewed. They often distinguished between making decisions and carrying out those decisions. Most of the people we spoke to depended to some extent on help from others to see these decisions through. Having control over their daily life depended on them having someone and, importantly, the right someone to help them.

For *accommodation cleanliness and comfort*, we used the wording "my home is clean and comfortable". Important aspects were having clean, dust-free surfaces and hygienic kitchens and bathrooms, but people also mentioned the state of the décor, whether their home was neat and tidy, whether their home had their own 'stuff' in it that they could get to readily and, also, whether they could get around their home easily. For example, a number of people mentioned the problems posed by stairs or mentioned how they had had their home adapted to make it easier for them to move around without help.

Dignity can mean many things to people, but "the way I think and feel about myself" captured a person's sense of self and significance well. Including "the way I'm helped and treated" meant that people considered the way their care and support packages affected their sense of self and significance. However, some people felt negatively about themselves not because of how they were treated but because it was difficult for them to accept that they needed help. Some of these people chose the 'no needs' answer but others chose one of the 'low or high level needs' answers. In order to investigate the impact of this on the measure and its interpretation, an additional question asking about the impact of 'having help at all' on how people feel about themselves will be included in the interviews with service users in the next stage.

We used the term "food and drink" for *meals and nutrition*. Including 'drink' was very important since people drink more often than they eat and many people discussed how they managed their lives to ensure they had the drink they needed. Initially, the wording was "I can get … the food and drink …" but we found that some people interpreted this too literally, as being physically able to get food and drink without help. We changed the wording to "I get … the food and drink …" which did not have the same problems.

"Doing things I value and enjoy" seemed to capture the type of things we intended for the *occupation* domain. People talked about voluntary work and paid work; activities they did with others, such as going out shopping or to eat; and activities they undertook on their own, such as reading, needlework or making cards. The answer options changed significantly from the first version of the question we tested in order to capture the frequency of doing things, the quality of the things done and the number of things people had to do. This is important as, for some people, the problem was not

that they did not have enough to do or things they enjoyed doing, but not being able to do as many things as they would like to undertake because of health limitations.

"Clean and presentable" was used for *personal cleanliness and comfort*, which was understood well by people. People talked about how frequently they washed, showered or bathed and also about whether they were able to fix their hair as they liked and wear the clothes they liked. Many of the women we interviewed talked about the difficulties they had with jewellery and make-up and how important it was for them to be able to wear them. The term 'poor personal hygiene' had been used in earlier versions and had been disliked by many who were consulted. We found that the revised version reflected this type of situation without using this term.

Feeling safe was understood by everyone, although some people questioned whether we meant did they feel safe outside or only inside their home. We have, therefore, recommended a prompt for interviewers to use or written guidance for self-completion versions to make it clear that we mean outside and inside the home.

We had some difficulty finding a good way of expressing *social participation and involvement* but settled on the phrase "social contact with people I like". As with the occupation domain, it is important to reflect the quality of contact, the frequency of contact and the number of people known to the person being interviewed. However, it was not possible to reflect all three aspects throughout the question and the quality part "people I like" was dropped from the last three options. This did not seem to matter: people continued to talk about contact with friends and family. They also mentioned phone, email and letter contact as well as face-to-face contact.

The original answer options also included the phrase "I feel lonely", but this was taken

out as it was confusing. As one person explained, "it depends on whether you mean personal or social life" as a person can be lonely because they do not have a special person in their life or lonely because they do not know many (or any) people. Given the areas over which social care can be expected to impact, we felt it was important to focus the question on the social rather than the personal side. We chose to use the term "socially isolated" to denote social loneliness and this appeared to work well.

We also tested including a time-frame in the answer options of "the past couple of weeks". However, we found that it made the question difficult for people to follow and, because many people had conditions that fluctuated over time, they tended to ignore the instruction even when it was pointed out to them. Most people preferred to answer according to an "average" day. We decided to leave these instructions out.

Differences between answer options

For the *dignity* and *safety* questions, it was clear that there was not enough difference in meaning between some of the levels. For *dignity,* the problem was with the bottom two levels, which were changed from "sometimes undermines" and "undermines" to "sometimes undermines" and "completely undermines". The bottom two levels of safety were also seen as quite similar. These were changed to "feel less than safe" and "don't feel at all safe" from "sometimes I don't feel safe enough" and "most of the time I don't feel safe enough". The top two levels of safety were also changed, with the second level changed to emphasise the sense of adequacy at that level.

The impact of services on quality of life

To measure outcomes from services we ask people to assess what their quality of life within each domain would be like without services. For each domain there are,

therefore, three questions: one question asks about the person's current quality of life; the second asks whether services help them in that domain; and the third asks what their life would be like without services (see Box 1). Previous studies and the cognitive testing with service users identified that, for the most part, people could visualise the hypothetical situation in the absence of services. It was important to clarify what services they were receiving prior to asking the questions and to reiterate that no-one else stepped in to compensate for the lack of those services. What was included as 'services' and the precise wording and guidance for interviewers would depend on the purpose of the study.

Living at home

In previous versions of the measure, and the one that we were proposing to take forward in the OSCA project, we included an additional domain 'living in your own home'. This was intended to reflect the fact that people would rather continue living in their own homes even, very often, with unmet needs, rather than live in a care home, and was an element of the key policy objective to keep people in their own homes wherever possible. This was only intended to be used as an indicator rather than a question that is part of the measure. Services would not be attributed with contributing to people living in their own home but to taking them away from their own home when care is provided in a communal living setting, with the score for this based on a weighting derived from the preference study.

Some potential problems with this were raised in the consultation process, including one respondent who pointed out there are a variety of living situations that could be reflected in this domain which might better be treated as 'living where you want'.

Box 1 Example of questions used in interview version for occupation domain

1. **Which of the following statements best describes how you spend your time?**

If respondent needs prompting please say: When you are thinking about how you spend your time, please include anything you value or enjoy including formal employment, voluntary or unpaid work, caring for others and leisure activities.

I'm able to spend my time as I want, doing things I value or enjoy ☐

I'm able do enough of the things I value or enjoy with my time ☐

I do some of the things I value or enjoy with my time but not enough ☐

I don't do anything I value or enjoy with my time ☐

2. **Do the support and services that you get from Social Services help you to spend your time doing things you value and enjoy?**

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<.... >> (definition reflecting context and objective of research)

Yes ☐

No ☐

Don't know ☐

If 2 = yes then

3. **Imagine that you didn't have the support and services from Social Services that you do now and no other help stepped in. In that situation, which of the following would best describe how you spend your time? Please assume that any other help you currently have would remain the same.**

NOTE to interviewer: if the person needs prompting or reminding please say by support and services that you get from Social Services, we mean <<.... >> (definition reflecting context and objective of research)
It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.
(Reassure if necessary: please be assured that this is purely imaginary and does not affect the services you receive in any way.)

I would be able to spend my time as I want, doing things I value or enjoy ☐

I wouldn't be able to do enough of the things I value or enjoy with my time ☐

I would do some of the things I value or enjoy with my time but not enough ☐

I wouldn't do anything I value or enjoy with my time ☐

In the cognitive testing, when service users imagined not living in their own home, they tended to imagine living in a care home. When we asked them to describe what this was like they described it in terms of the other aspects of quality of life that we already included in the measure, such as control over daily life, social participation and involvement, and so on. We felt that this could lead to confusion and that there was the potential for distorting choices and double-counting. This, together with the concerns raised in the consultation process, resulted in a decision to leave the domain out of the final measure.

Next steps

The instrument to be taken forward to the next stage of testing incorporates the lessons from the analysis of previous datasets, consultation and cognitive testing of the instrument to date. The aim of the next stage of the work is to test the psychometric properties, including the validity of our measure.

Ideally, at this stage, we would test the SCRQOL measure in a survey of all service user groups. In practice recruiting such a sample is far from straightforward, especially for a methodological study such as this. Service users are surveyed annually by local councils in the User Experience Survey (UES) but, to date, these surveys have focused on particular services or groups. As part of these surveys, councils often ask if respondents would be prepared to participate in further research. We took advantage of this in our project design and plan to recruit service users from the UES conducted in 2009 for the validation study.

In 2009, the UES is being conducted with older home care service users. This will allow us to test the reliability and validity of the measure in depth with this group, including the hypothetical 'expected needs or SCRQOL' scale. The aim is to achieve a sample of 300 people. We will be including

people who had help to complete the UES and exploring the impact of including other people (usually relatives and friends) to support and help people in responding to the questions because such support is frequently needed by people who use services. In 2010, the UES is being conducted with people who have received equipment in the preceding period. This includes people from all service user groups. We will be including the 'current state' instrument when interviewing service users about their preferences. This will facilitate further analysis of the performance of the questions and scale.

One of the issues that has been raised over the course of the project is that, while the objective is to make the measure applicable across all service user groups, the measure has not been tested with people with learning disabilities (who are unable to be involved in the type of cognitive testing undertaken to date) and there is only an English language version. We feel it is important to have a soundly based measure in terms of concepts and terminology before such developments. However, planned work as part of the development of the successor to the current UES is providing the opportunity to take things forward to some extent in these areas.

The aim is that, from 2011, the UES is intended to include all user groups and care settings each year, to reflect the transformational agenda on achieving personalised services and, importantly, the outcomes that people want. A significant problem that needs addressing when developing a questionnaire for such a diverse population is finding questions that make sense to everyone in that population and which are sensitive to differences in the quality of care provided. Previous UESs have tended to ask questions that focus on aspects of the process of care. The proposal is to include the self completion version of ASCOT in the survey and, as part of the development work, to develop a version that

is accessible for people with learning disabilities (Malley & Netten, 2009). The development work will also be focusing on the effect of help people receive to complete the questionnaire and the use of proxies, including when English is not spoken or understood. This should provide us with more evidence on practicality and validity of the use of the measure.

If included in the UES on a regular basis, the ASCOT measure will have the sound basis of the development work undertaken to date and planned under the OSCA project. Potentially, the ongoing information on SCRQOL outcomes over time for diverse groups and circumstances should provide a powerful point of comparison for a variety of purposes, including evaluation of national and local policy and practice.

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Notes on Contributors

Juliette Malley is a Research Officer at the Personal Social Services Research Unit (PSSRU) the University of Kent at Canterbury and the London School of Economics and Political Science. Her research interests are in the measurement and understanding of variations in quality and outcomes in social care. She is currently studying for a PhD, which is examining the use of survey-based user experience performance indicators in social care.

Ann Netten is Professor of Social Welfare and Director of the Kent branch of the Personal Social Services Research Unit. She has worked at the PSSRU since 1987. Her research interests include cost, quality and outcome measurement in social care, housing and care of older people and the costs of criminal justice interventions.

Address for Correspondence

Juliette Malley
Personal Social Services Research Unit
Department of Social Policy
London School of Economics & Political Science
Houghton Street
London
WC2A 2AE

Phone: 020 7955 6134
               01227 823877
Email: J.N.Malley@kent.ac.uk
               j.n.malley@lse.ac.uk