

Overview of outcome measurement for adults using social care services and support

Ann Netten

Methods Review 6

Improving the evidence base for
adult social care practice



The School for Social Care Research

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ABSTRACT

What is meant by outcome inevitably varies depending on the context and scope of what is under consideration. This review discusses the measurement of outcome for individuals and their carers for research purposes, particularly the type of research which evaluates the effectiveness and cost effectiveness of social care for adults and which has implications for social care practice. The review discusses what is meant by outcome in social care, presenting a model that describes different 'types' of outcome and how these are related to one another. Ultimately the objective is improving people's quality of life, and the review defines 'social care-related quality of life' as key to reflecting the impact of services. Some of the important challenges in measuring outcome in social care are identified: attribution, adaptation, reflecting the relative importance of the diverse aspects of quality of life and mental capacity and communication difficulties. The review then briefly describes practical approaches to measurement and concludes by making a number of recommendations for measuring outcomes in practice and the need for further methodological development.

RECOMMENDATIONS FOR RESEARCH ON ADULT SOCIAL CARE PRACTICE

- Ultimately the objective is to improve the quality of life of people who use services and support and of their carers. While changes in patterns of service use might be the objective of the intervention, they are not outcomes for people using services. To identify the outcomes of such interventions it is important to reflect their social care-related quality of life and/or well-being.
- In addition to the intended outcomes there will often be unintended outcomes, be they positive or negative. For this reason, and to improve the sensitivity of research studies in picking up effects, it is better to use more than one indicator of outcome. Ideally these measures link to the expected causal pathway of the intervention or focus of interest.
- Ideally, outcomes for carers would always be measured as well as for the individual. When that is not practical there should be acknowledgement of this impact and assumptions that are being made about such effects.
- Methodological work is needed to improve measurement of outcome in social care:
 - More evidence about the validity and reliability of measures in the social care context and for different service user groups.
 - Development in approaches for identifying outcomes for those for whom it is particularly challenging to do so – those with cognitive impairments and/or communication difficulties – is particularly pressing as these people comprise a high proportion of those who use social care.

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Evidence and methodological developments are needed to ensure valid comparisons are made across ratings and responses using different methods (including use of proxies) and by different user groups.

Individual aspects or domains of social care-related quality of life merit further investigation in terms of alternative approaches to measurement. Evidence about how measures of individual domains link to overarching SCRQoL measures, such as ASCOT, would enhance the value of both the measures and the research that uses them.

KEYWORDS

Outcomes, social care, quality of life, measurement, research methods

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INTRODUCTION

In social care, as in other fields, there is increasing emphasis on 'outcomes', but what is meant by outcome inevitably varies depending on the context and scope of what is under consideration. While social care can, and does, have an impact on the wider community, for example in terms of equity, in this review the discussion is limited to the impact on individuals, both those directly in receipt of social care interventions and their carers. Information about outcomes is needed for a number of purposes including policy evaluation, performance management and quality assurance. Here the focus is on research, particularly the type of research which evaluates the effectiveness and cost-effectiveness of social care for adults and which has implications for social care practice.

Although qualitative information about people's experiences and the effects of social care on their lives can provide illuminating insights, this review is concerned with measures that can be used in quantitative analysis. Measuring outcomes quantitatively is challenging in any field, but particularly so in social care. Fundamentally, outcomes are about impact – the effect of social care support. Even when we restrict ourselves to considering the impact on individual service users and their carers we need to be clear exactly what it is we are measuring. In the closely aligned field of health care, where outcome measurement is, arguably, much further developed, the starting point is presumably the impact on 'health'. What is the equivalent starting point in social care? What are social care services aiming to achieve? Like health, the ultimate aim is improvement in people's quality of life, but the means of achieving this and the focus are different. Again, fundamental to the measurement of outcome is the concept of comparison: identifying the difference between what would have happened in the absence of the intervention. However, the ongoing, long-term nature of much of social care poses particular problems of attribution; 'before and after' approaches will rarely reflect the impact of a social care intervention. People's situations may get worse even when services have made a substantial contribution. Even when interventions are more short-term, as can be the case in services that aim to be 'preventative', how do we identify the 'outcome' for an individual, when the aim is that something should not happen?

Some of these issues can be addressed through research design and careful analysis, but it is critical that the measures of outcome used are valid, reliable and, crucially, sensitive to the impact of social care. Although the ultimate aim might be better well-being or quality of life than would have occurred in the absence of an intervention there are usually a number of intervening objectives that we would want to measure to reflect the outcome of an intervention. These will include events or 'intermediate outcomes', such as whether people move into a care home, improvements in quality of care, and specific aspects of quality of life that are the focus of the intervention. It is important to understand the relationship between these different 'types' of outcome for the purposes of the research design, analysis and the interpretation of results.

For the results of research to be most widely useful in generating an evidence base it is

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helpful to have measures and results that can be compared across a wide range of circumstances. In the field of health the *quality-adjusted life year* (QALY) has proved particularly powerful because it facilitates comparisons across a wide range of health care interventions and can be directly related to costs, allowing evaluation of relative cost-effectiveness of a wide range of interventions. The QALY is based on measures of 'health-related quality of life' (HRQoL) which are 'preference-weighted' to reflect the relative importance of different aspects of HRQoL, to provide an indicator of the impact on people's well-being or utility. These weights are based on general population preferences for the different aspects of HRQoL reflected by the measure.

In social care the equivalent to HRQoL is *social care-related quality of life* (SCRQoL). What this encompasses is culturally and context-specific, with a move away from meeting needs towards more aspirational objectives increasing people's control over their care and support and their lives. Ideally, measures need to be able to reflect the degree to which social care is achieving such objectives, but there are many challenges in doing so, not least the problems presented in establishing the perspective of those with cognitive and communication problems, who form a substantial proportion of those who use social care services.

We start by considering what is meant by outcome in social care including different 'types' of outcome and how these are related to one another. Some of the challenges in measuring outcome in social care are identified followed by a brief description of and recommendations for measuring outcomes in practice.

WHAT DO WE MEAN BY OUTCOME IN SOCIAL CARE?

For users of services and support, social care is primarily concerned with mitigating the consequences of or compensating for impairment, whether the cause of that impairment is physical, mental or emotional. For carers,* social care is concerned with the knock on consequences for them of the impairments of those they care for. Qureshi and colleagues, (1998; Qureshi and Nicholas, 2001) distinguish three 'types' of outcome: maintenance, change and process. To these we might add 'prevention', which is increasingly being seen of critical importance. In each case we might ask 'of what?' For the most part the answer is about well-being or quality of life (QoL): maintaining or improving service user and carers' well-being. 'Process' outcomes, which Qureshi uses to include whether people feel treated as an individual, valued or respected, or whether services fit well with other sources of assistance, are important because we assume that they have an impact on people's well-being. Similarly, for some purposes events or services people receive might be treated as outcomes; for example, whether or not people are admitted to care homes or hospital. The underlying assumption when such events are treated as outcomes is that

* As we are discussing outcomes here, we are focusing on the impact of services and support on them rather than their role as providers of care (Twigg *et al.* 1990).

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people will experience a better quality of life by remaining in their own homes or not having to go into hospital – that these events or services are unnecessary. These types of outcome are *intermediate outcomes*, and assumptions about better quality of life need to be treated with caution as for many people the best option might be to move into a home or receive hospital treatment. The outcomes framework shown in Figure 1 and described below clarifies further the relationship between some of these ways of approaching and classifying outcomes.

Quality of life

Quality of life (QoL) is a complex concept due to its multiple perspectives and dimensions, and to the fact that it can be described and measured in many different ways (Schallock 1996). It is notoriously difficult to define as it encompasses many dimensions and can be viewed from a range of perspectives (Reed 2007). In the mid 1990s over 100 definitions and models of quality of life were identified (Cummins 1995) and they have multiplied since then. Forder *et al.* (2007) summarise the core ideas in the literature regarding the conceptualisation of QoL including domains of well-being; inter- and intra-personal variability; life-span factors and values; choices, control and empowerment.

With respect to QoL domains, Schallock's (2004) analysis of the literature found considerable agreement. Sixteen published studies analysed yielded a total of 125 indicators, the majority (74 per cent) of which related to eight core QoL domains:

- interpersonal relations;
- social inclusion;
- personal development;
- physical well-being;
- self-determination;
- material well-being;
- emotional well-being;
- rights.

Social care is not unique in being concerned with quality of life. Health, housing and other public services also have the ultimate objective of improving or maintaining quality of life. If we use too broad a measure of quality of life we may fail to pick up on effective social care interventions because of the confounding effects of other factors. The *extra-welfarist* approach sidesteps some of these problems by identifying what outcomes mandated decision-makers specify as important (Dolan and Edlin 2002, Birch and Donaldson 2003, Hansen *et al.* 2004, Culyer 2006). For example, government could decide that the aim of the health service is to improve population health. So although health services have effects that go beyond people's health, the outcome of health care is only assessed in these terms. Thus, rather than using global measure of quality of life, health outcome

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measures reflect *health-related quality of life* (HRQoL). In practice, health outcome measures range from very specific indicators linked to the impact of particular conditions, such as many of the Patient-Related Outcome Measures (PROMS), to broad measures, which combine HRQoL with mortality to reflect quality-adjusted life years (QALYs). The latter are intended to cover the full range of health outcomes to enable comparison across widely varying interventions.

HRQoL measures have the advantage that they are sensitive to health outcomes and reflect what is important to people in terms of the impact of poor health on their quality of life. As discussed below, the relative importance of these aspects of life is also reflected through weighting the scores to reflect population preferences. If we are to reflect the impact of social care on service users, clearly it would be useful to have the equivalent for social care.

Social care

If we are to define an equivalent to HRQoL for social care we need to be more specific about what it is that social care does and aims to do. Social care is primarily about compensating for impairment, so people who have problems doing things for themselves can be personally clean and groomed, get all the food and drink they want and need, see people enough and so on. *Social care-related quality of life* (SCRQoL) will be culturally defined, may change over time and can be deduced by observation of what services do and consultation with those in receipt of services and support. For example, for older people, home help services used to be focused primarily on household cleanliness and comfort with some personal care. In the 1990s there was a policy shift away from what was seen as 'low-level' household support to more intensive services focused on personal care (Netten *et al.* 2002). This shifted to more emphasis on 'prevention', social inclusion and most recently on giving people choice and control (Department of Health 2005, Department of Health 2009).

This shift in emphasis to choice and control has implications beyond the types of domain that we need to include in SCRQoL. Sen (1985) argues that utility (or experienced quality of life derived from functionings) 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. Traditionally social care has been concerned with meeting needs, which could be represented as particular functioning states (such as being well fed or safe). The more aspirational agenda reflected in policy documents such as *Putting People First* (Department of Health 2009) suggests that in measuring outcomes in the future we need to reflect the impact on capabilities. Similarly, the *National Carer Strategy* (Department of Health 2008) emphasises the importance of carers having 'a life of their own'. Lewis and Giullari (2005) argue that the capabilities approach is promising ground for establishing a basis on which to address the issue of care, where 'a life of one's own' raises complex issues about the value of care, gender equalities and trade-offs between care and paid work.

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Social care-related quality of life

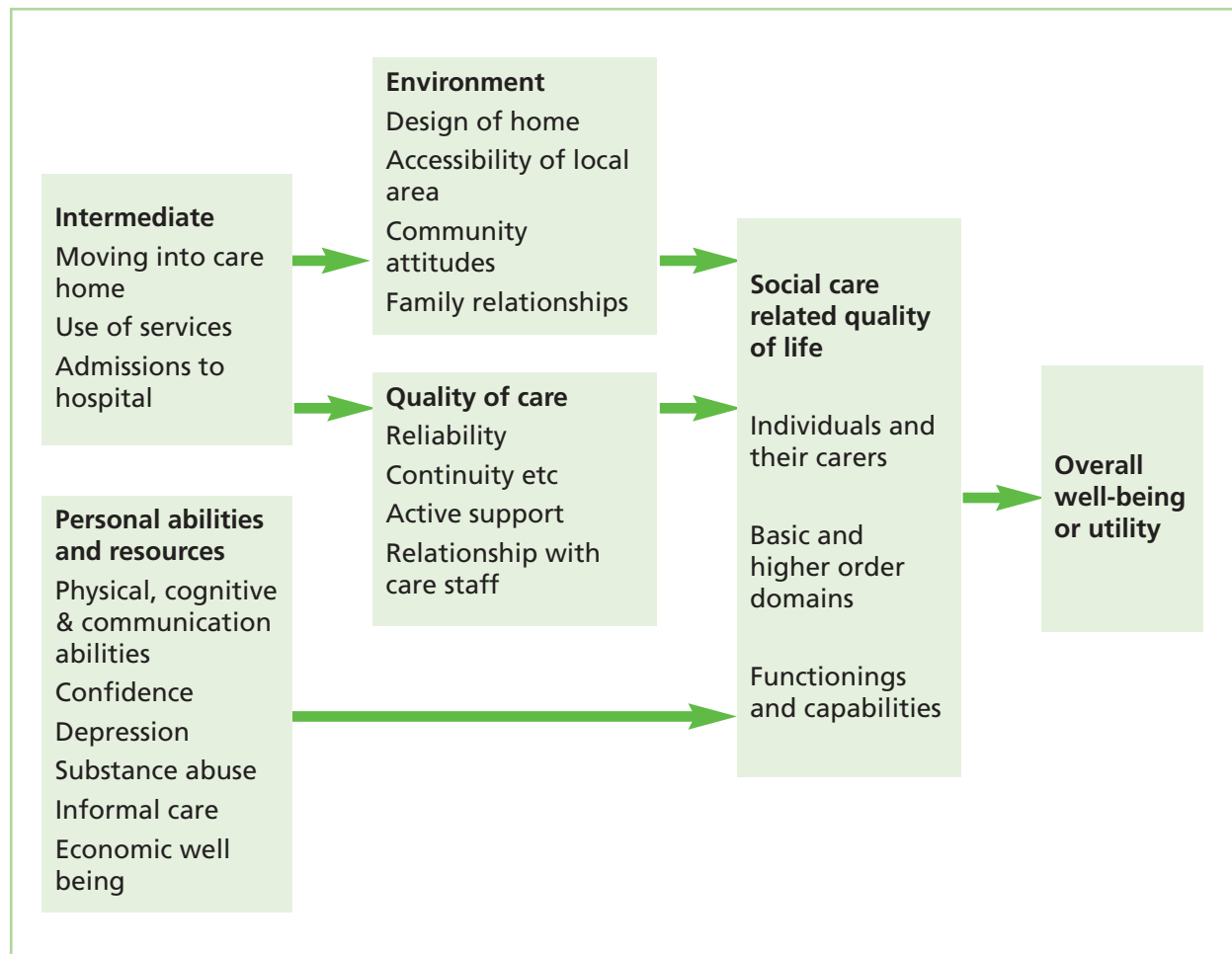
Table 1 shows the domains of SCRQoL that have been derived from a series of studies and now form the basis of the Adult Social Care Outcome Toolkit (ASCOT) (Netten *et al.* 2010a). The first four – personal, cleanliness and comfort, accommodation cleanliness and comfort, food and drink, and feeling safe – can be seen as ‘basic’ aspects of quality of life. The next three – social participation, occupation and control – as higher order, perhaps less easily achieved domains. The last – ‘dignity’ – is the only one that is specific to care and relates to the aspect of the process that would not be expected to be reflected in the other domains – the impact of the way the care and support are provided on people’s self esteem.

Table 1: Domains of social care-related quality of life

Domain	Definition
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
Accommodation cleanliness and comfort	The service user feels their home environment, including all the rooms, is clean and comfortable
Food and drink	The service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food and drink he/she enjoys at regular and timely intervals
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
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
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

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Figure 1: Outcomes framework



There are clearly other aspects of quality of life that have been identified as policy objectives or are the focus of social care interventions. In some instances these might be aspects of domains that it may well be important to measure in more depth or distinguish separately. For example, employment, parenting and caring for others are particular aspects of occupation that are likely to be the focus of interventions aimed at younger age groups. Where people are living in their own homes, in communal settings or with parents or others, this can be seen as a separate domain (identified as ‘living where you want’ (Miller *et al.* 2008)), or one that should be encapsulated by other domains (Netten *et al.* 2009). In other cases the focus of the intervention may be on changing the environment, quality of care or personal circumstances of individuals and their care networks.

The outcomes framework in Figure 1 illustrates the relationship between these different types of outcome. The impact of intermediate outcomes, such as maintaining people in their own homes, will depend on levels of impairment, resources available, the quality of the immediate and surrounding environment, and quality of care provided. The

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environment includes physical surroundings and the social context. Social context includes the general social climate or atmosphere of a care facility and individuals' relationships with their families and social networks, which might be the target of a family intervention (see for example Leff *et al.* 1989).

In this framework the outcomes for the individual and their carer are shown together, although clearly these will influence each other and in some cases there will be trade-offs between these outcomes. Similarly, there may be trade-offs between different aspects of SCRQoL for individuals. For example, social care interventions can often require trade-offs between people's safety and control over their daily lives. While an overarching preference-weighted measure can assist in evaluating overall impact, for some purposes we might be more interested in individual measures of different aspects of SCRQoL to provide a more in-depth picture of the effect of an intervention and/or such trade-offs.

The framework shows psychological well-being, sometime described as 'happiness' or 'morale', as related to SCRQoL in two ways. First, the SCRQoL domains would be expected to affect people's overall quality of life, happiness or morale; that is, how improved levels of happiness (or absence of depression) and so on are achieved by social care interventions. Second, low levels of confidence or morale, or presence of depression, can generate needs in our domains, and the process of improving confidence or morale (which some interventions may directly act on) can then result in better outcomes in our domains and thus overall quality of life.

Policy outcomes are often phrased in terms of maximising people's independence, ensuring economic well-being and so on. Once clearly defined, such outcomes can be mapped on to this framework. 'Economic well-being' reflects the financial resources the individual can draw on. 'Independence', often used in the policy context and by people themselves, is a term that is defined differently by different people, depending on their own personal contexts (Fisk and Abbott 1998). The term independence is often taken to mean maintaining people in their own homes, but for people in need of a lot of care and support moving into care homes can result in improved well-being and outcomes (Bebbington *et al.* 2001).

Relationship with health and other sectors

Personal and contextual characteristics, such as communication abilities and abilities to undertake activities of daily living, are factors that will affect SCRQoL and thus be legitimate targets of a social care intervention. However, improving or maintaining these are also sometimes the objectives of health services. So, for example, health services are concerned with treatment and mitigation of impairment to provide rehabilitation services and speech and language therapy that should improve people's abilities in activities of daily living and communication abilities. Social care services are about ensuring that people are personally clean, have social contact and so on. When the means of achieving this is best served through improving people's own abilities, social and health care services are complementary and (ideally) work very closely with each other, and boundaries

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between agency responsibilities will be legitimately blurred. Similarly, local authority housing and environment departments have responsibilities for ensuring accessibility but tackling environmental barriers may be the best way to achieve social care objectives. Personal development, which is an aspect of quality of life particularly noted in the field of learning disability, can be the objective and result of both education and social care interventions.

In addition to activities of other agencies having social care consequences, social care has implications for health outcomes. Poor SCRQoL outcomes potentially have serious health implications. For example, social isolation has been demonstrated to have impacts on morbidity and even mortality (Patterson and Veestra 2010). Lack of food and drink has health implications, with older people often suffering from malnutrition and dehydration on admission to hospital which has knock-on consequences for their treatment and health more generally (Age Concern 2006, Edington *et al.* 2000) and in extreme circumstances people can and do starve to death. Lower-level interventions have also been shown to have beneficial health outcomes (Windle *et al.* 2010). For example, befriending can reduce social isolation and reduce symptoms of depression (Mead *et al.* 2010). While often the focus of social care preventative services is on intermediate outcomes, such as reductions in the need for acute health services, we would also expect to see the benefits in better health-related quality of life.

The index of capability (ICECAP) measure was developed to reflect health and social care outcomes for older people (Coast *et al.* 2008a, 2008b). This is a preference-weighted quality of life indicator, which provides a good broad indicator of people's capabilities and general well-being. While the measure is likely to be related to variations in health state and social care-related quality of life, the domains are very broadly defined and do not specify basic aspects of quality of life that social care addresses such as food and drink.

Outcomes for different user groups and carers

Social care literature tends for the most part to focus on specific service user groups, which are based on the type of impairment and/or age. At least in theory SCRQoL measures are applicable across all user groups, but the nature of impairment and history of service development mean that some domains may seem more or less relevant to different groups. For example, food and drink are important in the care of older people (Netten *et al.* 2002) but are not often the focus of interventions for younger people with learning disabilities, a group where the focus is often on domains of occupation, social participation and control (Miller *et al.* 2008, Mansell *et al.* 2005). As identified above for younger groups, the occupation domain is often identified as of particular importance, but has generally been treated by policy makers and services as less relevant to older people. In the field of learning disability, personal development may be an objective of social care interventions and, although related to occupation, the outcome might be better measured in terms of changes in personal abilities and resources (Beadle-Brown *et al.* 2006).

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For people with mental health problems, where health and social care services are often closely integrated, the distinction and separate measurement of social care-related quality of life may not be seen as of particular relevance. Improvements in both the cause and consequence of the social care-related need (see Figure 1) can be represented as the target of the intervention. Quality of life measures are often good indicators of the extent of mental health problems (Barry and Zissi 1997) and so may be all that is needed for many purposes. In terms of the individual domains, more basic domains such as personal cleanliness and comfort only tend to become so when people have very acute mental health problems. In terms of SCRQoL, the focus is more often related to ‘higher-order’ domains such as occupation and social participation. A number of studies of mental health interventions have used indicators of social functioning as outcomes. These could be considered equally relevant to social care and reflect the current interest in social capital (Lin 2008). Essentially these approaches are based on social role theory so that a person not functioning as would be expected to meet the (social determined) norms of their situation could be considered not to be functioning well. Examples include social functioning subscales in well-known tools (Ware *et al.* 1997), and specific measures of social functioning and adjustment (Kedward and Syplh 1974, Clare and Cairns 1978, Remington and Tyrer 1979). With greater policy concerns about social inclusion and integration, there has been work to capture the range, quality and extent of social networks (Henderson *et al.* 1980, Brown and Harris 1978) which again could constitute the basis both of outcomes in their own right and as determinants of other outcomes.

For carers the ‘impairment’ could be thought of as the demands of the caring role, and outcomes are often conceptualised in terms of reduction of burden, whether this be opportunity cost or psychological burden. However, there is increased emphasis on quality of life of carers, which can include the positive aspects of the caring role. There are a wide range of instruments that are intended to reflect carer burden, experiences, needs and quality of life (see Deekin *et al.* 2003 and Harvey *et al.* 2008, for example). It is arguable that the same domains of SCRQoL identified for service users are relevant to carers (Fox *et al.* 2010), although terminology in measurement might be different.

These variations in emphasis have implications for both the relative importance of different domains or aspects of SCRQoL and the range of measures that might be relevant to include in an evaluation. This is discussed further when we turn to challenges for measurement of outcomes below.

Unintended consequences

Interventions can and do have unintended consequences. These will include effects on others, perhaps increasing burden on carers or other family members, and negative outcomes, such as reducing people’s sense of control or dignity. Indeed it is arguable that, once we allow for the beneficial impact of services and support on the primary domains of SCRQoL listed in Table 1, personal cleanliness, social participation and so on, they have more potential to undermine people’s dignity than to enhance it.

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Obviously it is difficult to anticipate unintended consequences, but it is important to be aware that these may occur and to identify how these would potentially be picked up through research instruments and design. For example, as part of the Individual Budget (IB) pilot evaluation, a measure of psychological well (or ill) being, the General Health Questionnaire (GHQ12) (Goldberg 1972), was included as one indicator of outcome. This picked up significantly lower psychological well-being amongst older people receiving IBs compared with mainstream services. The authors suggested that this might be due in part to the stage in the process at which people were interviewed, possibly reflecting levels of anxiety about managing the budget and organising their own support (Glendinning *et al.* 2008). There may also be knock-on wider consequences, for example increases in unmet need among those not targeted by an intervention, which could have important implications for wider roll-out, and which may be difficult to establish within an individual evaluation. In such instances the immediate evaluation might include a qualitative investigation that provides indications of whether this was a likely outcome and thus a need for further work.

CHALLENGES IN MEASUREMENT

Ideally in measuring outcomes we want valid, reliable, sensitive indicators that accurately reflect the impact of social care interventions. This is enormously challenging, but it is important that we measure the right thing in the right way or we are in danger of missing important effects or (arguably less likely) falsely attributing effects where they do not exist.

We have identified above that the fundamental objective of social care is to improve people's quality of life. Whether we define this broadly or more narrowly as SCRQoL, and whether we reflect functionings or capabilities, the challenges in this process include:

- attribution
- adaptation
- reflecting the relative importance of the diverse aspects of QoL
- mental capacity and communication difficulties.

We start by considering the implications and ways of addressing these problems before identifying ways of measuring outcomes in practice.

Attribution

As identified above, the key objective in measuring outcomes is to reflect the impact of the intervention. Some of the means by which we ensure that we are correctly attributing outcomes to interventions are about research design, which is beyond the scope of this review. However, there are implications for the measures used and interpretations of findings.

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For example, essentially we want to know the counterfactual: what would have happened in the absence of the intervention. Most people in receipt of publicly funded social care have at least moderate or high levels of need. However, people rarely approach social care agencies for the first time in these need states without some sort of support from elsewhere. We also want to know about outcomes for people who have been in receipt of services and support for some time, whose circumstances will have changed since they started receiving them. Before-and-after measurement is likely to underestimate the impact of flexible interventions that respond to changes in needs. Randomised or matched comparison groups, particularly together with multivariate analyses, can adjust for the impact of factors expected to affect outcomes. However, such designs can be resource-intensive and any effects established just reflect the marginal difference rather than the full impact of the intervention.

For many purposes, for example comparing a new intervention with mainstream services, reflecting marginal differences in outcome will be sufficient. However, the ongoing nature of most social care has the advantage that, unlike many health care treatments, service users themselves will often have a clear idea about what their situation would be in the absence of services. The Adult Social Care Outcome Toolkit takes advantage of this by incorporating an 'expected' measure which can be used to establish a measure of SCRQoL gain (see below). However, this type of approach is more challenging when interventions are one-off or intermittent, like respite care or breaks for carers. The Personal Budgets Outcome Evaluation Tool (POET) approach, advocated by In Control (www.incontrol.org) attempts to ensure attribution by asking people directly if different aspects of their life and support are better or worse as a result of having a personal budget (Hatton and Waters 2011).

An indirect approach to reflecting outcomes, also used in the ASCOT toolkit, is that of separating the potential of services from what they do actually deliver. This draws on the concept of expected needs in the absence of intervention. A given intervention has capacity for benefit (CfB) depending on the number of people helped, the domains of outcome in which it can help them and the degree to which those using the service rely on it for those outcomes. Individuals have the capacity to benefit (CtB) from interventions, measured as their expected needs or SCRQoL in the absence of the intervention and the level of SCRQoL that could be achieved if that intervention was perfect (usually assumed to be the top level in each domain). In order to reflect what is actually delivered in practice, a quality measure monitors actual levels of need or experienced SCRQoL. As CtB is closely correlated with more routinely used measures of activities of daily life (ADL), level of service received and receipt of support from other sources, this can be monitored using low burden or routinely available indicators. This has the advantage that an indicator of the value of the service or outcome-weighted outputs can be generated without overburdening individuals or agencies. This approach has been developed for the purposes of monitoring the productivity of services rather than evaluation.

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Adaptation

When measuring outcomes in terms of happiness or quality of life another problem is that of *adaptation*, a concept developed in the psychology literature. The argument is that people adapt in the way they experience functionings in their life according to the circumstances in which they find themselves. When these circumstances get worse, people are less happy initially because their functionings are lower and their perceptions of these functionings have not yet changed. After time however, they adapt and they find more pleasure than before from the lower levels of functionings. So whilst functionings are lower, people get more from this poorer set of functionings. This means that the reporting of levels of well-being or quality of life is context-specific (Kahneman and Kreuger 2006). For example, people with high levels of impairment will often report good self-perceived health as they have adapted to their circumstances.

Similar to the adaptation or 'hedonic treadmill' hypothesis as it is sometimes called, is the idea of a 'satisfaction' treadmill (Kahneman *et al.* 1999). Instead of people's adaptation level changing, their *aspiration level* changes, that is, their satisfaction with their experiences. So, as a person's situation improves and their experienced functionings improve, their well-being increases (discounting any hedonic treadmill effect), but after some time, their aspirations regarding this experience also increase. Because their aspirations become re-aligned with their experiences, satisfaction falls back to original levels. People expect to be better off as their circumstances improve, and would be unhappy if their experiences were not as least as good as their expectations (Forder *et al.* 2007).

In social care, in addition to adaptation there is the problem of long-standing low expectations and functionings. People who have had very poor levels of functioning throughout their lives may have no concept that it might be possible for them to achieve higher levels, so will 'experience' them as relatively high. For example, people who have lived for a long time in poor communal settings or with low levels of support simply cannot envisage a level of control or occupation any higher than that which they have. People with learning disabilities have reported higher levels of quality of life than others when asked the same questions (Glendinning *et al.* 2008). It is arguable whether this reflects a genuinely better quality of life, lack of intellectual capacity, a judgement based on lack of opportunity to experience higher levels of functioning or whether people are being influenced in their responses by others present at the time they are asked (perhaps not wanting to offend) (Heal and Sigelman 1995).

Measuring and weighting

How to measure such a difficult concept as quality of life is very challenging and diverse approaches have been employed. In *hedonic psychology* well-being or utility is regarded as directly measurable. People can be asked directly how happy they feel or how satisfied they are with their lives, identify where they feel they are with respect to these on a visual analogue scale, or, in the 'new' hedonics approach, report their momentary or *instant*

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utility. In this instant utility approach, momentary experiences are summed to give a total utility or quality of life indicator reflecting people's experiences over the period being measured. This is termed a measure of 'objective happiness' as the way that the moments are sampled and added up is according to objective rules – the judgements or ratings are obviously subjective (Kahneman 2000). Proponents of momentary sampling approaches argue that the recall and interpretation of events required, which can lead to bias or inaccuracy in global ratings or measures, are avoided. However, it can be argued that both global recall questions or ratings and summing experiences into this type of single dimension measure are too reductionist (Kelman 2004). Moreover, when understanding the impact of social care, reflecting the effects of interventions on different dimensions of outcome is valuable when drawing implications for social care practice.

Multi-item measures can reflect the different dimensions or domains of outcome; however, to use these in analyses to identify the overall impact on outcome we then have the problem of how to combine the scores for each item. Multi-item measures drawn from the psychological literature tend to focus on ensuring reliability in reflecting an underlying construct, such as depression, morale, control and so on, and so include a number of items to reflect each aspect of that construct. In deriving the measure of the construct or overall QoL each item is weighted the same, so there is an underlying assumption that these are of equivalent importance.

In the health economics literature, when reflecting HRQoL, measures are now usually preference-weighted in order to reflect the value of the outcome state. In preference-weighted measures, rather than a single construct, items are intended to reflect orthogonal or distinctly separate domains that can be independently distinguished with a minimum of overlap (Brazier *et al.* 2007). A variety of techniques have been used to establish preference weights (for example, standard gamble, time trade off (TTO), discrete choice experiments (DCE), Best Worst Scaling (BWS) and contingent valuation). In social care preference weights have been derived for the Older Person's Utility Scale (OPUS) measure (Ryan *et al.* 2006) using DCE, and for versions of the ASCOT measure using DCE and BWS (Burge *et al.* 2010a, Burge *et al.* 2010b).

It is helpful to anchor measures to a common metric to enable comparison across very different interventions and groups. In health, QALYs reflect both length of life and quality of that life, with HRQoL weights anchored to the 'dead' state (scored as 0, with some health states identified as negative: worse than death). Thus, the measure can legitimately be linked to time, providing a basis to compare outcomes with different lengths of time in different health states. All QALY measures (for example EQ5D, various versions of the Health Utility Index (HUI) and the reduced version of the SF36 (the SF6 see Brazier *et al.* 2004)) are by definition anchored in this way. In social care, as increase in life expectancy is not a direct outcome, it could be argued that this is not an appropriate anchor. However, a measure anchored in this way does potentially provide read-over to health outcomes and has a wider range of applications, including the value of preventative services in delaying onset of higher-level need states. The ASCOT measure now provides this facility as the

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scoring is now anchored in this way, with 0 reflecting 'being dead' and 1 the 'ideal' SCRQoL state (www.pssru.ac.uk/ascot; Netten *et al.* forthcoming).

Alternatively, contingent valuation identifies how much people would be prepared to pay for (or accept rather than) being in different situations. In this instance the measure is anchored to money so, arguably, could be used in cost-benefit or similar analyses where outcomes are valued in financial terms. In social care, a pilot study included a DCE exercise on a precursor of the ASCOT including a financial attribute, allowing a financial valuation to be made for each outcome state (Burge *et al.* 2010a).

For the most part, preference weights are based on studies using general population samples. The argument is that these are most appropriate when the results of studies are used to allocate public resources funded through general taxation. However, patient and service user views are not necessarily the same as those of the general population, so it can be argued that whose views should be used to reflect the relative importance of different domains depends on the purpose of the study (Williams 1991). However, work to date suggest this is less of an issue in social care, where service user preferences for SCRQoL states do not appear to differ from those of the general population (Netten *et al.* forthcoming).

While preference-weighted measures do provide us with more information about the domains of outcome as well as a single overall indicator of outcome, there are, of course criticisms of this approach. The number of items tends to be limited and, partly as a consequence, measures such as EQ5D have been criticised as being insensitive to certain conditions, for example mental health problems (Roike *et al.* 2004). The preference elicitation process requires that people predict how they would feel in different circumstances and the evidence is that people are not good at this – partly as a result of the adaptation process described above.

Measures such as the Schedule for the Evaluation of Individual Quality of Life (SEIQOL) (O'Boyle *et al.* 1995, Hickey *et al.* 1996) and the Patient Generated Index (PGI) (Ruta *et al.* 1994) attempt to get round this by asking people to choose the domains that are important to them in relation to the service being evaluated (from a master list) and then score levels of achievement in those domains. Respondents then select their own weights for the relative importance of the domains. The approach is based on social judgement theory, and respondents need to have sufficient insight into the factors that determine their quality of life, ability to think abstractly, and, for SEIQOL, the ability to make judgements based on information presented in diagrams.

In order for such measures to accurately reflect the relative importance of individually specified aspects of their lives and to provide robust, comparable, valid, reliable and sensitive results, the process tends to be very demanding of respondents. This brings us to the next major challenge in measuring outcomes in social care: the abilities of people who use services to communicate their own views and perspectives.

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Mental capacity and communication

Over half of all those responding to user experience surveys which use self-completion questionnaires had help to complete these (Malley *et al.* 2010a), and while in many instances this help will be relatively minor, for many others their voice will not be heard if alternative means are not found to establish their views and experiences. Structured interviews can reach people with a wider range of abilities but a substantial proportion of people who use social care services have moderate or severe cognitive impairment in the form of learning disabilities, dementia or other problems. Many of these and other people have other communication difficulties which make it particularly challenging to establish their views about their lives and experiences.

There are a number of ways to address this issue. Proxy informants can be used – carers or others who know people well can answer questions on their behalf. The DEMQOL measure (Banerjee *et al.* 2006, Smith *et al.* 2007) attempts to include such aspects in assessing HRQoL of people with dementia for people with all types of care arrangements and all stages of dementia. This instrument asks questions of both the person with dementia and his or her carer relating to the individual's feelings or mood, concerns about memory and cognitive loss and their experience of help and relationships with others. It is recommended that both measures are used, although testing suggested that for people with severe dementia, only the proxy version should be used.

The degree to which items can be answered on behalf of others depends on whether they are perception-based or evaluation-based (Schwartz and Rapkin 2004). Perception-based questions, which ask about observable facts, such as how often people see others, might be answered reasonably reliably. Evaluation-based questions, which ask about people's views – such as whether they feel in control of their lives – require people to have a framework within which to evaluate. As a result they are much less reliably established through proxy informants who are likely to be influenced by other factors than the experience of that individual, including relationships and their own physical and mental status (Dabbs 1999, Twining 1991).

There is no doubt that most people can express their views in some way, and that we should draw on this as far as possible (Mozley *et al.* 1999). The problem is finding systematic ways to record the information for the more severely impaired so it is useable in a quantitative research context. Other approaches to establishing people's views include Talking Mats (<http://www.talkingmats.com>), which can facilitate communication with people with severe communication difficulties and help in generating qualitative information about people's experiences. However, considerable investment would need to be undertaken before a reliable quantitative measure could be generated using such techniques.

Observation-based techniques can provide another perspective on people's experiences. Dementia Care Mapping (DCM), based on psychosocial theories of dementia (Kitwood 1997), was developed following extensive observations in a variety of settings (Bradford

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Dementia Group 2002) and has been mainly used as a tool for practice development. It has been validated as a research tool for measuring quality of life in people with dementia living in care homes (Fossey *et al.* 2002). This provides detailed, operationalised ratings of individuals' well-being and activities, recorded systematically every five minutes, in the full version over a period of six hours. Training in the process is important to ensure ratings are made consistently. Well-being is rated on a scale reflecting engagement, self-expression and social interaction.

Observation has also been an important approach in the field of learning disabilities. Here the focus has also been on engagement, activities and relationships, for example the momentary time sampling measures of engagement in meaningful activities and relationships (EMACR) (Beasley *et al.* 1993, Mansell and Beadle-Brown 2005) used by Mansell and colleagues (2008) or the continuous real-time multiple-category recording (Emerson *et al.* 2000) which has been used in work by Jones and colleagues (1999) and by Stancliffe and colleagues (2007). In most of the recent work using these measures observations have been for a shorter time period (two hours) and often based around an evening meal. Again training is important to ensure consistency and reliability.

The ASCOT measure is intended to be usable across all service user groups and care settings, but uses different tools to reflect the variations in people's abilities to participate in the research process. As such a high proportion of people living in care homes have severe cognitive impairment and/or communication difficulties, a multi-method approach is recommended, using semi-structured interviews with staff and residents and a period of structured observation. This information is then used to rate current and expected SCRQoL on the dimensions listed in Table 1 (Netten *et al.* 2010b). Guidance is provided, and training recommended, in order to ensure adequate inter-rater reliability (www.PSSRU.ac.uk/ASCOT).

MEASURING OUTCOMES IN PRACTICE

While ultimately the aim of social care is to improve or maintain well-being or quality of life, it is clearly important that when measuring outcomes in practice that the measures are sensitive to the objective of the intervention of interest. For example, if the aim is to improve well-being through creating a more facilitative environment, we need to be able to identify whether the environment is perceived as more facilitative, as well as distinguishing any differences in well-being. A number of different types of outcome have been distinguished in Figure 1 above. In considering how outcomes are or could be measured in practice in social care research we look at each of these types of outcome in turn.

Intermediate outcomes

Intermediate outcomes are usually indicators of events, such as moving into a care home or hospital stays. The national evaluation for the Partnerships for Older People Pilots

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(POPP) (Windle *et al.* 2009) demonstrated this effect, comparing admissions to hospital in areas where the intervention had taken place with matched areas where it did not. As identified above, there is an implicit assumption in using such measures that evidence of prevention of such events is an indicator of positive benefit to the individuals concerned. This is particularly powerful because in addition to this assumed benefit, there are often associated cost implications (as in the case of the POPP evaluation), so interventions that deliver such outcomes can be seen as both reducing costs and improving outcomes.

It is important that other measures of outcome are used to complement such relatively crude indicators (as was done in the POPP evaluation). As identified above, prevention of use of a service could mean that people who need that service have unmet needs and overall well-being might be lower as a result. Nevertheless, it is difficult to establish outcomes of prevention – in terms of lack of deterioration – so this type of indicator, when supplemented with other outcome information, can be very helpful.

Personal abilities and resource outcomes

For the most part personal abilities and resources are inputs into the production of social care rather than outcomes, but when the objective is to change these factors, through enablement services perhaps, or to prevent deterioration, measures of personal abilities can and have been used to reflect the outcomes of social care interventions. Measures of these will often be specific to the particular type of impairment or individual circumstances, so types of the measure may vary with service user group.

Before-and-after measures are particularly relevant to interventions that have change as their objective, such as enablement services. Abilities in activities of daily living (ADLs) can be measured through a straightforward count of ADLs for which help is needed or through specific measures such as Barthel (Mahoney and Barthel 1965) and Katz *et al.* (1963, 1970) for people with physical impairments or SABS (Beadle-Brown *et al.* 2008, 2009) for people with learning disabilities. While simple counts appear to work well as indicators of impairment, measures such as Barthel have the advantage that previous research has identified how large a change reflects a significant difference in individuals' levels of ability (Collin *et al.* 1988) and has been used to track changes in residents' abilities in a longitudinal study of care homes (Bebbington *et al.* 2001). The Minimum Data Set residential assessment instrument (MDS-RAI) (Morris *et al.* 1994) and the community version (MDS-HC) (Morris *et al.* 1997) are widely used by care services internationally to monitor changes in service users' health state and mental and cognitive impairment and can be used as indicators of outcome (Carpenter *et al.* 2002). EQ5D also provides an indicator of needs that is closely associated with ADLs, with additional domains covering pain, anxiety and depression (Brazier *et al.* 2004). It is widely used as a measure of health outcome and included in a number of data collections such as Health Survey for England, giving it the advantage of allowing comparisons with the general population. This was also used in the POPPs evaluation (Windle *et al.* 2009).

Behaviours, such as substance abuse, can lead to social care needs. Treatment tends to be

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primarily health service provision, but could well be the objective of social care interventions, with a focus on domains such as occupation (employment) and social participation. Behaviour such as substance abuse is often linked to mental health problems and poor psychological health, including lack of confidence and depression, and can of themselves result in social care needs. Changes in depressive symptoms and other indicators of psychological well (or ill) being are obvious candidates for measuring outcome for people with mental health problems. However, they are most commonly used as indicators of overall psychological well-being and are discussed below as indicators of overall quality of life.

Changes in opportunity costs to carers, or time spent caring could be regarded as indicators of outcome for carers. However, as with intermediate outcomes, the assumption underlying this is that carer well-being would be increased through such reductions. In a study comparing carers of people receiving Individual Budgets (IBs) with people receiving mainstream services, carers of people with IBs spent at least as much time caring but reported better quality of life. This suggests that it may be how the time is spent and other factors rather than the time or opportunity cost *per se* (Glendinning *et al.* 2008).

For both service users and carers the concept of economic well-being as an outcome has been used in policy (Department of Health, 2005). One approach is simply to ask people whether they feel that caring, for example, has caused them any financial difficulties (Fox *et al.* 2010). This at least picks up on people's perceptions, if not 'economic well-being' as such. Responses to questions about what people perceive as an adequate or reasonable level of income are very dependent on individual circumstances and expectations. Questions about actual levels of income tend to have lower levels of response and attributing any differences or changes to service interventions is far from straightforward. However, when the objective is clearly linked to the source of income, for example information and advice services that focus on improving uptake of welfare benefits, this type of measure is relevant.

Environmental outcomes

Changing the physical or social environment to enhance individuals' well-being can be the objective of social care interventions, and thus measuring changes in these would be an important element of outcome in their evaluation. Measuring the physical environment is far from straightforward, and in evaluation terms has for the most part been treated as contextual information or an aspect of inputs. Simple indicators of people's perceptions of their environment include single questions that ask people how they feel about their immediate home and local environment (Malley *et al.* 2010a). These have been found to be associated with social care-related quality of life domains (Netten *et al.* 2010a) so both offer potential indicators of change and helpful context to interpretation of SCRQoL outcomes.

In residential or institutional settings the general social atmosphere or climate might again be an objective of interest or change. The Multiphasic Environment Assessment Procedure (MEAP) includes the Sheltered Care Environment Scale (SCES) (Moos and Lemke

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1984, 1992), developed in the US, which has been used in care homes for older people in the UK (see for example Mozley *et al.* 2004). Again, such measures have tended to be treated as context or inputs for the most part, but changes in these could be considered as outcomes and/or part of the 'mechanism' of how an intervention is intended to achieve improvements in quality of life.

Quality of care outcomes and satisfaction

Rather than the environment more generally, social care interventions are more frequently centred on improving the quality of care provided. In the field of care homes for older people, Davies and Heath (2007) review a variety of approaches that have been used to measuring care home quality. This includes the combined assessment of residential environments (CARE) assessment tools based on the Senses Framework developed by Nolan and colleagues (2009) which uses individual profiling tools to determine the perspective of older people, their relatives and the staff. The 'senses' cover security, continuity, belonging, purpose, achievement and significance (Nolan *et al.* 2009). Such attributes are difficult to establish for people with dementia, but Dementia Care Mapping (DCM), based on Kitwood's (1997) theory of dementia, provides structured data on how staff are interacting with residents in ways that can be used to identify care outcomes (Beavis *et al.* 2002).

In the field of learning disabilities there is a lot of focus on active support which is a method of supporting people on a day-to-day basis to improve their participation in activities and relationships and thus their quality of life. The focus is on the facilitative assistance staff give people to be involved. The extent of implementation has been measured using observation of engagement, processes and systems used by staff and by the Active Support Measure (ASM) which evaluates the quality of staff support for user participation (Stancliffe *et al.* 2008, Mansell *et al.* 2005, Mansell and Elliott 1996). In community services, sets of questions used as part of the national User Experience Surveys (UES) have been found to work well as indicators of quality in the field of home care of older people (Jones *et al.* 2007) and applicable for the most part to younger adults with physical and sensory impairments (Malley *et al.* 2006).

Another approach to reflecting quality of a service is to measure satisfaction with that service. There are some problems with using satisfaction as an indicator of quality of care as satisfaction may be influenced by aspects other than quality, such as users' expectations (Shaw 1984, Coulter 2005). There is a tendency for people, particularly older people, to report very high levels of satisfaction, making it difficult to distinguish variations in quality (Bauld *et al.* 2000). However, a single item with seven options has been shown to be significantly associated with variations in quality for home care for older people. Four different levels of quality were identified. The top three levels (extremely, very and quite satisfied) were associated with significantly different levels of quality. Very poor quality was reflected when people responded that they were neither satisfied nor dissatisfied or with any level of dissatisfaction (Jones *et al.* 2007). Subsequent analysis suggested some

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instability in that relationship, although it was likely that this was related to using the satisfaction indicator as a performance indicator (Malley and Netten 2008). In the absence of this, the indicator can provide a quick and easy indicator of people's perceptions of the help and support they receive.

There are limitations, however. For people with learning disabilities seven options proved too many for them to cope with, and even a collapsed five-level version was seen as challenging (Malley *et al.* 2010a). Moreover, with general measures of satisfaction it is not entirely clear what people are taking into account and, as satisfaction is so linked to expectations, the measure is particularly vulnerable to adaptation effects as described above. SERVQUAL, which has been used in nursing homes in the US (Duffy *et al.* 2001), provides a rather more detailed measure of people's perceptions of quality which has components that identify expectations specifically, providing potential for evaluating how these have changed and how satisfaction links to expectations.

Social care-related quality of life outcomes

The close link between health and social care means that measures developed for the purposes of measuring health outcomes are often relevant in social care. There is a wide diversity of such measures (see for example, McDowell 2006, Bowling 2001). However it is important to be clear what is actually being measured in terms of the framework shown in Figure 1. Clinical outcome measures may focus on specific domains, for example nutritional status and the food and drink domain shown in Table 1, and can be highly relevant, although they are rarely used in practice. Self-report indicators are often described as measures of quality of life, but often are closer to indicators of personal abilities and resources in the framework in Figure 1, focusing on aspects of functional ability. Where the objective is compensation, such measures are likely to be insensitive to impact of a social care intervention.

In fields such as mental health, where health and social care outcomes are very closely aligned, indicators of mood and/or social functioning and relationships are potentially very useful (Goldberg 1972, Clare and Cairns 1978, Goldman *et al.* 1992, Henderson *et al.* 1980, Remington and Tyer 1979, Ware *et al.* 1997). Indicators of psychological health developed for people with mental health problems often provide helpful indicators of overall well-being more generally (see below).

Each of the SCRQoL domains shown in Table 1 is each broad and multi-faceted and the impact of an intervention on each of these, or combinations of them, could be individually measured. This is particularly appropriate where there is a specific interest in the impact on that aspect of people's lives. For example, interventions which are particularly focused on social participation and involvement may best be evaluated using measures that reflect loneliness, involvement in the local community, social capital, social networks and so on.

In some instances the focus of interest is in a construct that covers a subset of SCRQoL domains. For example, 'engagement' of people with learning disabilities is seen as

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particularly important (Mansell *et al.* 2005, 2008). Engagement can be seen as covering all the 'higher order' domains of SCRQoL (control, occupation, social participation and involvement – with good support for engagement ensuring no loss of and ideally improvements in self-esteem) what has been defined above as 'dignity'. These are just the domains that are least well measured through proxies, so observational approaches such as EMACR (Mansell and Beadle-Brown 2005) are useful when these aspects of quality of life are the focus of the study or intervention for people with limited mental capacity and/or communication difficulties.

While measures of individual aspects or subsets of SCRQoL domains are helpful in identifying the degree to which an intervention is having an intended impact, a broad-based measure of SCRQoL used alongside more focused indicators can identify both unintended consequences and, if preference-weighted, assist in understanding the impact of trade-offs between different aspects of SCRQoL.

ASCOT

The only measure currently that explicitly aims to reflect overall SCRQoL across the full range of user groups and care settings is the ASCOT measure, versions of which have been used in a variety of studies including the national evaluation of Individual Budget pilots (Glendinning *et al.* 2008), a study of day care of older people (Caiels *et al.* 2010) and care homes for older people and people with learning disabilities (Netten *et al.* 2010b). The items that comprise the measure are included in the Adult Social Care Survey (ASCS), which is conducted by all local councils with social services responsibilities in England, with the aim of covering all service user groups each year (The Information Centre 2010), potentially providing a valuable set of benchmarking data. At the time of writing there are plans to use some of the items (safety and control) and the equally weighted overall measure as part of the Adult Social Care Outcomes Framework (Department of Health 2011). The domains in ASCOT are shown in Table 1. At least in theory, in the most recent version of the measure the four response options for each domain are intended to identify functionings (what is actually happening to people) at lower levels of SCRQoL and capabilities (whether what is happening reflects their personal preferences) at higher levels. The rationale for this is that, however far a person has adapted to that situation, social care interventions should be offered when there are observable needs, particularly when there might be a health implication if these needs are not met. Once there are no real needs the distinction is between an 'adequate' or 'mustn't grumble' state and an 'ideal' or 'desired' state. At this point the focus is on capabilities – are people where they want to be in that aspect of their lives (Netten *et al.* 2009)?

The ASCOT measure can be preference-weighted, with measures of current, expected or gain in SCRQoL identified through a variety of tools including self-completion questionnaires, interviews and multi-method-based ratings including observation for care homes (www.pssru.as.uk/ASCOT). Figure 2 illustrates the outcomes achieved drawing on the instrument. The darker area reflects SCRQoL in the absence of services (in this instance

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Figure 2: Older adults’ outcomes: current and expected SCRQOL



Note: SCRQOL shown as percentage of total possible score for each domain

care homes for older people) and the lighter shaded area the contribution of services (Netten *et al.* 2010a).* This demonstrates both where services have most effect and those areas (primarily the ‘higher order’ domains) where the impact is limited.

The ASCOT measure provides a useful overall indicator that enables comparisons to be made across a range of interventions and client groups, but each domain is only reflected in a single item. While in some instances these individual items can be useful – for example, in the IB evaluation higher levels of control were identified among those receiving IBs using this item (Glendinning *et al.* 2008) – for many purposes more sensitive, in-depth measures of domains may be required. For example, there are a number of different scales and sub-scales that aim to pick up people’s sense of control. The domain of social participation and involvement also covers many different aspects of social well-being. After cognitive testing, the ASCOT measure moved away from using loneliness as an element as it too often reflected an aspect of bereavement that it is not within the

* The dignity domain is not included as it only applies in the presence of services. In the absence of services in the composite measure the weight reflecting no impact on self-esteem is used.

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power of social care to address. However, understanding how lonely people feel, the degree to which they are involved in and feel part of their community, the level of social contact that they have with people that they like, existence of a confidante and their relationships with others may all be seen as dimensions that are important to reflect to fully understand when social participation is the focus of a study or intervention.

Information and advice

There is increasing emphasis on the role of social care services in providing or facilitating access to information and advice. Such services can be represented as having short, intermediate and long-term outcomes. Short-term outcomes are the immediate impact on the recipient's well-being; intermediate outcomes the actions (or non-actions) that are taken as a result; and long-term outcomes the impact of those actions on individuals' quality of life (Netten and Forder 2008). It is far from straightforward to attribute long-term outcomes and there is a risk of double counting benefits when the activities involve accessing other services. However, through modelling it is possible to link intermediate actions to longer term outcomes, for example the impact of debt advice on people with mental health problems (Knapp *et al.* 2011). Some work has been undertaken on developing indicators of short-term outcomes of information advice and advocacy* services (Windle *et al.* 2010). Consultation with service users, providers and other stakeholders identified knowledge, empowerment and reduction in anxiety as short-term outcomes, which are applicable across a wide range of information and advice services, but in the context here are most closely aligned to social care-related quality of life. A tool reflecting these has been tested with services (Windle *et al.* 2010) and proved reasonably successful. However, there are a number of hurdles yet to be addressed in measuring outcomes of these services, which tend to be very process- rather than outcome-oriented. Challenges include achieving good response rates with groups that tend to be hard to reach.

Carer outcomes

Most social care studies of carers have focused on the impact of services intended to provide respite or breaks for them. However, ideally when measuring the outcomes of any intervention we would include measuring the impact on carers. As identified above, the level and way services are provided for the people they are caring for will affect their quality of life and some measures have been developed with the express aim of reflecting their well-being as a carer, or carer SCRQoL.

The impact of health conditions on carers means that a variety of measures have been developed to reflect carers' experiences. A literature search in 2004 identified 45 measures of carer outcomes, of which 16 were measures of caregiver burden (Visser-Meily *et al.*

* Limiting advocacy to short-term activities on behalf of individuals, rather than the longer-term development of a relationship.

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2004). However, about half of the measures were just used once. The more widely used include, for example, the Carer Malaise Inventory (Rutter *et al.* 1970), which has been used in studies of mainstream services for older people (Davies *et al.* 1990, Bauld *et al.* 2000). However, there is an increased acknowledgement that there are benefits to the person providing care and some measures also include domains reflecting the positive aspects of caring (for example, McKee *et al.* 2003). The recently developed Adult Carer Quality of Life Questionnaire (AC-QoL) (Elwick *et al.* 2010) has 40 items with eight sub-scales reflecting both positive and negative aspects of how caring relates to carers' quality of life, and as a result would be expected to be sensitive to carer focused interventions.

An adapted version of the ASCOT SCRQoL measure was used to reflect carer outcome in the evaluation of the impact of Individual Budgets on carers (Glendinning *et al.* 2008). Subsequently work was undertaken with carers exploring the relevance and comprehensiveness of the ASCOT domains of SCRQoL to carers in reflecting the impact of services for them and for those they care for (Fox *et al.* 2010). Questions that were developed and tested during this work have been used in a local (Smith *et al.* 2009) and national Carer Experience Survey (Fox *et al.* 2010). A measure based on these questions appears to demonstrate good internal reliability (Smith *et al.* 2010, Malley *et al.* 2010b). Plans to include these items in a regular national carer survey feeding into the Adult Social Care Outcome Framework from 2012 (Department of Health 2011) mean that in future national data may be available providing a potentially useful benchmark or basis for comparison.

The only preference-weighted measure currently available for use in economic evaluations that is focused on the caring experience is the Care Experience Scale (Al-Janabi *et al.* 2008, 2011). This newly developed measure is part of the ICECAP 'family' of measures (www.icecap.bham.ac.uk) and has five items, each reflecting a different aspect of care, including support from others.

Overall well-being

As has been argued above, ultimately the aim of social care is to improve the overall well-being of people with impairment and that of those who care for them, and this can be defined or distinguished in a number of different ways. One approach is to use measures of psychological well-being. Such measures have often been developed to detect mental ill-health so could better be described in some ways as indicators of psychological ill health. GHQ12, for example, has a cut-off score below which it is likely the person is clinically depressed (Goldberg 1978), although it has been tested as a measure of positive mental health in the general population (Hu *et al.* 2007). There is clearly circularity, illustrated in Figure 1, in that such psychological ill-health or low morale might be the main or contributory factor to social care needs. However, as long as the expected causal pathways are clearly defined and the research design allows for other factors associated with variation, such measures can be and have been used to good effect in distinguishing the impact of social care interventions.

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GHQ12 has been used in a number of studies including the impact of breaks on carers (Levin *et al.* 1994) and evaluating the impact of Individual Budgets on service users (Glendinning *et al.* 2008). One advantage of the measure is that it was included in the Health Survey for England (2010) and the British National Household Panel Survey (BHPS) (2010), providing a basis for comparison between the general population and service users. Some measures have been used that have been developed specifically to reflect the morale or psychological well-being of older people. For example, the Philadelphia Geriatric Centre Morale Scale (Lawton 1975) was used in studies of case management (Challis and Davies 1986) and a large-scale study of services for older people (Davies *et al.* 1990, Bauld *et al.* 2000). CASP19, also developed for use with older people (Hyde *et al.* 2003), has been used in studies of extra-care housing and retirement villages (Bernard *et al.* 2004, Callaghan *et al.* 2009). CASP19 has the advantage of having been used in national data collection, in this case the longitudinal survey of ageing (Blane *et al.* 2008).

An alternative approach is to attempt to reflect overall quality of life. While not suitable for use without other indicators, a single question asking people to rate their overall quality of life can be used to provide a general sense of impact on well-being overall. A seven-point item was used as part of the Individual Budget evaluation and proved sensitive for people with mental health problems to differences between those receiving IBs and those receiving mainstream services (Glendinning *et al.* 2008). The approach of reflecting overall utility through momentary time sampling has yet to be used in social care, and it is not clear how feasible this would be for many service users.

More sensitive indicators reflect the different domains of quality of life. Such measures include the Lancashire Quality of Life Profile (LQOLP), the residential version of which has been used in evaluating residential care of older people (Mozley *et al.* 2004). This study found that it was possible to interview a number of residents using this instrument despite quite high levels of cognitive impairment as measured by the Mini Mental State Examination (MMSE). As identified above DEMQOL is an instrument that could be used to measure quality of life of people with dementia which uses proxy respondents to ensure the full range of impairment can be covered. Observational approaches include the well-being and ill-being profiling (Bradford Dementia Group 2002).

In the area of learning disabilities there has been, and continues to be, debate about the validity and methodology for assessing quality of life (Beadle-Brown *et al.* 2009). In this field particularly, the distinction is drawn between 'objective' measures – ratings by others – and 'subjective' measures of life satisfaction. Cummins (2001) maintains that measuring subjective ratings of quality of life and life satisfaction is important, while others question its usefulness (Ager and Hatton 1999, Hensel 2001). As in the field of care of people with dementia, observational approaches have been developed which go some way to address such challenges (Mansell *et al.* 2005, Emerson *et al.* 2000).

RECOMMENDATIONS

Measuring social care outcomes is far from straightforward. Much will depend on the intervention or focus of interest and the range of types and circumstances of people involved. Outcomes will not be the same for everyone so it is important to distinguish what characteristics are associated with what outcomes. The research design and analysis will be key to distinguishing and attributing such effects. However, there are some general recommendations that can be made.

First, it is important that whatever measures are used are sensitive to the objective of the intervention or focus of interest. In social care that means that health-related quality of life indicators, such as EQ5D, are only likely to be relevant when the objectives are to target people's personal abilities, such as preventative or rehabilitation services. In most social care contexts health-related quality of life measures are indicators of need, an alternative to ADL measures rather than an indicator outcome (Caiels *et al.* 2010). SCRQoL measures should, by definition, be more sensitive to outcome. These may be global indicators (as in ASCOT) and/or more specific, relating to particular domains or sets of domains of SCRQoL.

Clearly measures need to be valid and reliable. While no attempt has been made here to review measures in these terms, ideally there should be evidence of reliability and validity of the measure with the target population. The dearth of evaluative research including outcome measurement in social care means that this may not always be possible. Providing evidence about the performance of measures as part of evaluative studies would help increase this evidence base.

While changes in patterns of service use might be the objective of the intervention, they are not outcomes for people using services. Underlying such changes may or may not be improvements in the well-being of individuals and their carers. To identify the outcomes of such interventions it is important to reflect their impact on social care-related quality of life and/or well-being. Ideally to interpret the impact, indicators are also needed of personal abilities and resources, environment and quality of care (see Figure 1).

Social care interventions are usually complex and it is likely that in addition to the intended outcomes there will be unintended outcomes, be they positive or negative. For this reason, and to improve the sensitivity of research studies in picking up effects, it is better to use more than one indicator of outcome. Ideally these measures link to the expected causal pathway of the intervention or focus of interest. The outcomes framework in Figure 1 might be helpful in deciding the types of measure that may be useful.

Social care interventions usually have an impact on people caring for individuals as well as the individuals themselves. Ideally, outcomes for carers would always be measured as well as for the individual. Often that is not practicable because of resource constraints but there should be acknowledgement of this impact and assumptions that are being made about such effects.

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Many people who use social care services and support are not able to complete questionnaires or take part in interviews using the type of structured questionnaires used for most quantitative analyses. While proxy respondents can provide some information, they bring their own perspective and it is particularly difficult to establish reliable information about personal evaluations such as sense of control, feelings about their social life and how they spend their time. Observational techniques can be valuable in providing quantitative data about these aspects of people's lives and multi-method approaches drawing on a number of sources can also be used to help to make ratings.

While this review has identified a number of approaches to measurement of outcome there clearly remains a lot of methodological work to be done. The need for more evidence about the validity and reliability of measures in the social care context and for different service user groups has been identified above. Further development in methodological approaches for identifying outcomes for those for whom it is particularly challenging to do so - those with cognitive impairments and/or communication difficulties - is particularly pressing as these people form such a substantial proportion of those who use social care. If we are to make best use of evidence on outcomes, more work is also needed to assist us in making valid comparisons in ratings and responses across methods (including use of proxies) and different user groups. The domains of social care-related quality of life listed in Table 1 could be regarded as an agenda for future research in themselves. Each of those merits further investigation in terms of alternative approaches to measurement. Evidence about how measures of these domains link to overarching SCRQoL measures, such as ASCOT, would enhance the value of both the measures and the research that uses them.

Fundamentally, the aim of social care is to improve, or at least maintain the quality of people's lives. Rapid changes are taking place in approaches to arranging and providing social care. If we are to understand how successful current practice and new developments are, and how to improve them, we must include measures of outcome that both reflect and inform us about the nature of that impact. This review provides some insight into measuring the impact on individuals. Reflecting the wider impact on the community provides yet further challenges to the researcher.

Overview of outcome measurement for adults using social care services and support

References

Age Concern (2006) *Hungry to be Heard: The Scandal of Malnourished Older People in Hospital*, Age Concern England, London.

Ager A, Hatton C (1999) Discerning the appropriate role and status of “quality of life” assessment for persons with intellectual disability: a reply to Cummins, *Journal of Applied Research in Intellectual Disabilities*, 12, 335–339.

Al-Janabi H, Coast J, Flynn TN (2008) What do people value when they provide unpaid care? A meta-ethnography with interview follow-up, *Social Science and Medicine*, 67, 111–121.

Al-Janabi H, Flynn T, Coast J (2011) Estimation of a preference-based Carer Experience Scale, *Medical Decision Making*, 31, 3, 458–468.

Banerjee S, Smith SC, Lamping DL, Harwood RH, Foley B, Smith P, Murray J, Prince M, Levin E, Knapp M (2006) Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia, *Journal of Neurology, Neurosurgery and Psychiatry*, 77, 146–148.

Barry MM, Zissi A (1997) Quality of life as an outcome measure in evaluating mental health services: A review of the empirical evidence, *Social Psychiatry and Psychiatric Epidemiology*, 32, 1, 38–47.

Bauld L, Chesterman J, Judge K (2000) Measuring satisfaction with social care amongst older service users: issues from the literature, *Health & Social Care in the Community*, 8, 5, 316–324.

Beadle-Brown J, Murphy G, Wing L (2006) The Camberwell Cohort 25 years on: characteristics and changes in skills over time, *Journal of Applied Research in Intellectual Disability*, 19, 317–329.

Beadle-Brown J, Hutchison A, Whelton B (2008) A better life: the implementation and effect of person-centred active support in the Avenues Trust, *Tizard Learning Disability Review*, 13, 4, 15–24.

Beadle-Brown J, Murphy G, DiTerlizzi M (2009) Quality of Life for the Camberwell Cohort: a brief report, *Journal of Applied Research in Intellectual Disability*, 22, 380–390.

Beasley F, Hewson S, Mansell J, Hughes D, Stein J (1993) *MTS: Handbook for Observers (4th Edition)*, Tizard Centre, University of Kent, Canterbury.

Beavis D, Simpson S, Graham I (2002) A literature review of dementia care mapping: methodological considerations and efficacy, *Journal of Psychiatric and Mental Health Nursing*, 9, 6, 725–736.

Overview of outcome measurement for adults using social care services and support

Bebbington A, Darton R, Netten A (2001) *Care Homes for Older People: Volume 2. Admissions, Needs and Outcomes*, Personal Social Services Research Unit, University of Kent, Canterbury.

Bernard M, Bartlam B, Biggs S, Sim J (2004) *New Lifestyles in Old Age: Health, Identity and Well-being in Berryhill Retirement Village*, Policy Press, Bristol.

Birch S, Donaldson C (2003) Valuing the benefits and costs of health care programmes: where's the `extra` in extra-welfarism?, *Social Science and Medicine*, 56, 5, 1121–1133.

Blane D, Netuveli G, Montgomery S (2008) Quality of life, health and physiological status and change at older ages, *Social Science and Medicine*, 66, 7, 1579–1587.

Bowling A (2001) *Measuring Disease: A Review of Disease Specific Quality of Life Measurement Scales (2nd edition)*, Open University Press, Buckingham.

Bradford Dementia Group (2002) *Well-Being Profiling Tool*, University of Bradford, Bradford.

Brazier J, Roberts J, Tsuchiyaa A, Busschbach J (2004) A comparison of the EQ-5D and SF-6D across seven patient groups, *Health Economics*, 13, 873–884.

Brazier J, Ratcliffe J, Tsuchiya A, Salomon J (2007) *Measuring and Valuing Health Benefits for Economic Evaluation*, Oxford University Press, Oxford.

British Household Panel Survey (BHPS) (2010)
<http://www.poverty.org.uk/technical/bhps.shtml>

Brown GW, Harris T (1978) *Social Origins of Depression: A Study of Psychiatric Disorder in Women*, Tavistock, London.

Burge P, Netten A, Gallo F (2010a) Estimating the value of social care, *Journal of Health Economics*, 29, 883–94.

Burge P, Potoglou D, Kim C, Hess S (2010b) *How do the Public Value Different Outcomes of Social Care?*, *Estimation of preference weights for ASCOT*, RAND working paper, Rand Europe, Cambridge.

Caiels J, Forder J, Malley J, Netten A, Windle K (2010) *Measuring the Outcome of Low-Level Services: Final Report*, PSSRU Discussion Paper No. 2699, Personal Social Services Research Unit, University of Kent, Canterbury.

Callaghan L, Netten A, Darton R (2009) *The Development of Social Well-Being in New Extra Care Housing Schemes*, Report for Joseph Rowntree Foundation, Joseph Rowntree Foundation, York.

Carpenter GI, Field J, Challis D, Swift C (2002) Routine use of standardised assessment for monitoring the outcomes of community-based care, *Age and Ageing*, 31, Supplement 1, 34.

Overview of outcome measurement for adults using social care services and support

Challis D, Davies B (1986) *Case Management in Community Care*, Ashgate, Aldershot.

Clare A, Cairns V (1978) Design, development and use of a standardized interview to assess social maladjustment and dysfunction in community studies, *Psychological Medicine*, 8, 589-604.

Coast J, Flynn T, Natarajan L, Sproston K, Lewis J, Louviere J, Peters T (2008a) Valuing the ICECAP capability index for older people, *Social Science & Medicine*, 67, 5, 874–882.

Coast J, Peters T, Natarajan L, Sproston K, Flynn, T (2008b) An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people, *Quality of Life Research*, 17, 7, 967–976.

Collin C, Wade DT, Davies S, Horne V (1988) The Barthel ADL Index: a reliability study, *International Disability Studies*, 10, 2, 61–63.

Coulter A (2005) *Trends in Patients' Experience of the NHS*, The Picker Institute, Oxford.

Culyer A (2006) *Rationing Health Care and the Dilemmas it Poses – Some Pale Reflections on an Agenda of Alan Williams. Be Reasonable: Following the Williams' Way*, Centre for Health Economics, York.

Cummins RA (1995) Assessing quality of life, in Brown RI (ed.) *Quality of Life for Handicapped People*, Croom Helm, London.

Cummins RA (2001) Self-rated scales quality of life scales for people with an intellectual disability: a reply to Ager and Hatton, *Journal of Applied Research in Intellectual Disabilities*, 14, 1–11.

Dabbs C (1999) What do people with dementia most value in life?, *Journal of Dementia Care*, July/August, 16–19.

Davies B, Bebbington A, Charnley H (1990) *Resources, Needs and Outcomes in Community-based Care*, Avebury, Aldershot.

Davies S, Heath H (2007) *Quality of Care, My Home Life, Quality of Life in Care Homes*, Help the Aged, London.

Deeken JF, Taylor KL, Mangan P, Yabroff KR, Ingham JM (2003) Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers, *Journal of Pain Symptom Management*, 26, 4, 922–953.

Department of Health (2005) *Independence Well-Being and Choice*, Department of Health, London.

Department of Health (2008) *Carers at the Heart of 21st Century – Families and Communities*, HM Government, London.

Overview of outcome measurement for adults using social care services and support

Department of Health (2009) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*, HM Government, London.

Department of Health (2011) *Transparency in Outcomes: A Framework for Quality in Adult Social Care – Response to Consultation*, HM Government, London.

Dolan P, Edlin R (2002) Is it really possible to build a bridge between cost-benefit analysis and cost-effectiveness analysis?, *Journal of Health Economics*, 21, 5, 827–843.

Duffy JA, Duffy M, Kilbourne M (2001) A comparative study of resident, family, and administrator expectations for service quality in nursing homes, *Health Care Management Review*, 26, 3, 75–85.

Edington J, Boorman J, Durrant ER, Perkins A, Giffin CV, James R, Thomson JM, Oldroyd JC, Smith JC, Torrance AD, Blackshaw V, Green S, Hills CJ, Berry C, McKenzie C, Vicca N, Ward JE, Coles SJ (2000) Prevalence of malnutrition on admission to four hospitals in England, The Malnutrition Prevalence Group, *Clinical Nutrition*, 19, 191, 5.

Elwick H, Joseph S, Becker S, Becker F (2010) *Manual for the Adult Carer quality of Life Questionnaire (AC-QoL)*, The Princess Royal Trust for Carers in association with the School of Sociology and Social Policy, The University of Nottingham, Nottingham.

Emerson E, Reeves DJ, Felce D (2000) Palmtop computer technologies for behavioral observation research, in Thompson T, Felce D, Symons FJ (eds) *Behavioral Observation: Technology and Applications in Developmental Disabilities*, Paul H. Brookes, Baltimore.

Fisk M, Abbot S (1998) Older people and the meaning of independence, *Generations Review*, 8, 2, 9–10.

Forder J, Netten A, Caiels J, Smith J, Malley J (2007) *Theoretical Concepts in Assessing the Outcomes of Social Care*, PSSRU Discussion Paper No. 2480, Personal Social Services Research Unit, University of Kent, Canterbury.

Fossey J, Lee L, Ballard C (2002) Dementia Care Mapping as a research tool for measuring quality of life in care settings: psychometric properties International, *Journal of Geriatric Psychiatry*, 17, 1064–1070.

Fox D, Holder J, Netten A (2010) *Carer's Experience Survey 2009–2010: Survey Development Project*, PSSRU Discussion Paper No. 2643/2, Personal Social Services Research Unit, University of Kent, Canterbury.

Glendinning C, Challis D, Fernández JL, Jacobs S, Jones K, Knapp M, Manthorpe J, Moran C, Netten A, Stevens M, Wilberforce M (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*, Social Policy Research Unit, University of York.

Goldberg D (1972) *The Detection of Psychiatric Illness by Questionnaire*, Oxford University Press, London.

Overview of outcome measurement for adults using social care services and support

Goldberg D (1978) *Manual of General Health Questionnaire*, National Federation of Educational Research Publishing Company, Windsor.

Goldman HH, Skodol AE, Lave TR (1992) Revising axis V for DSM-IV: A review of measures of social functioning, *American Journal of Psychiatry*, 149, 1148–1156.

Hansen B, Hougaard J, Keiding H, Osterdal L (2004) On the possibility of a bridge between CBA and CEA: comments on a paper by Dolan and Edlin, *Journal of Health Economics*, 23, 5, 887–898.

Harvey K, Catty J, Langman A, Winfield H, Clement S, Burns E, White S, Burns T (2008) A review of instruments developed to measure outcomes for carers of people with mental health problems, *Acta Psychiatrica Scandinavica*, 117, 3, 164–176.

Hatton C, Waters J (2011) *The National Personal Budget Survey*, In Control and Lancaster University.

Heal L, Sigelman C (1995) Response biases in interviews of individuals with limited mental ability, *Journal of Intellectual Disability Research*, 29, 4, 331–340.

Health Survey for England (2010) <http://www.esds.ac.uk/government/hse/>

Henderson S, Duncan-Jones P, Byrne DG, Scott R (1980) Measuring social relationships: The interview schedule for social interaction, *Psychological Medicine*, 10, 723–734.

Hensel E (2001) Is satisfaction a valid concept in the assessment of quality of life of people with intellectual disabilities? A review of the literature, *Journal of Applied Research in Intellectual Disabilities*, 14, 311–326.

Hickey A, Bury G, O'Boyle C, Bradley F, O'Kelly F, Shannon W (1996) A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS, *British Medical Journal*, 313, 29–33.

Hu Y, Stewart-Brown SL, Twigg L, Weich S (2007) Can the 12-item General Health Questionnaire be used to measure positive mental health?, *Psychological Medicine*, 37, 7, 1005–1013.

Hyde M, Wiggins RD, Higgs P, Blane DB (2003) A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19), *Aging and Mental Health*, 7, 3, 186–194.

Jones E, Perry J, Low K, Felce D, Toogood S, Dunstan F, Allen D, Pagler J (1999) Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support, *Journal of Intellectual Disability Research*, 43, 3, 164–178.

Overview of outcome measurement for adults using social care services and support

Jones K, Netten A, Francis J, Bebbington A (2007) Incorporating older service user experiences in performance monitoring of home care, *Health and Social Care*, 15, 4, 322–332.

Kahneman D (2000) Experienced utility and objective happiness: a moment-based approach, in Kahneman D, Tversky A (eds) *Choices, Values and Frames*, Cambridge University Press, New York.

Kahneman D, Krueger AB (2006) Developments in the measurement of subjective well-being, *Journal of Economic Perspectives*, 20, 1, 3–24.

Kahneman D, Diener E, Schwarz N (eds) (1999) *Well-Being: The Foundations of Hedonic Psychology*, Russell Sage Foundation, New York.

Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW (1963) Studies of illness in the aged, The Index of ADL: a standardized measure of biological and psychosocial function, *Journal of the American Medical Association*, 185, 12, 914–919.

Katz S, Downs TD, Cash HR, Grotz RC (1970) Progress in development of the index of ADL, *Gerontologist*, 10, 1, 20–30.

Kedward HB, Sylph JA (1974) Social correlates of chronic neurotic disorder, *Social Psychiatry*, 9, 91–98.

Kelman M (2004) Hedonic psychology, political theory, and law: Is welfarism possible?, *Buffalo Law Review*, 52, 1, 1–84.

Kitwood T (1997) *Dementia Reconsidered: The Person Comes First*, Open University Press, Buckingham.

Knapp M, McDaid D, Evans-Lacko S, Fitch C, King D (2011) Debt, mental illness and counselling: cost-effectiveness analysis, submitted for publication.

Lawton MP (1975) Philadelphia Geriatric Center Morale Scale – revision, *Journals of Gerontology*, 30, 1, 85–89.

Leff J, Berkowitz R, Shavit N, Strachan A, Glass I, Vaughn C (1989) A trial of family therapy v. a relative's group for schizophrenia, *British Journal of Psychiatry*, 154, 58–66.

Levin E, Moriarty J, Gorbach P (1994) *Better for the Break*, HMSO, London.

Lewis J, Giullari S (2005) The adult worker model family, gender equality and care: the search for new policy principles and the possibilities and problems of a capabilities approach, *Economy and Society*, 34, 1, 76–104.

Lin N (2008) Building a network theory of social capital, in Lin N, Cook K, Burt RS (eds) *Social Capital: Theory and Research*, Transaction Publishers, New Jersey.

Overview of outcome measurement for adults using social care services and support

Mahoney FI, Barthel DW (1965) Functional evaluation: The Barthel Index, *Maryland State Medical Journal*, 14, 61–65.

Malley J, Netten A (2008) Measuring and monitoring outputs in social care: the problem of measuring quality, *International Review of Administrative Sciences*, 74, 4, 535–553.

Malley J, Sandhu S, Netten A (2006) *Younger Adults' Understanding of Questions for a Service User Experience Survey*, Report to Health and Social Care Information Centre, PSSRU Discussion Paper No. 2360, Personal Social Services Research Unit, University of Kent, Canterbury.

Malley J, Caiels J, Fox D, McCarthy M, Smith N, Beadle-Brown J, Netten A, Marie Towers (née Muncer) A (2010a) *A Report on the Development Studies for the National Social Care User Experience Survey*, PSSRU Discussion Paper No. 2721, Personal Social Services Research Unit, University of Kent.

Malley J, Fox D, Netten A (2010b) *Developing a Carer's Experience Performance Indicator*, PSSRU Discussion Paper No. 2734, Personal Social Services Research Unit, University of Kent, Canterbury.

Mansell J, Beadle-Brown J (2005) *Engagement in Meaningful Activities and Relationship: Handbook for Observers*, Tizard Centre, University of Kent, Canterbury.

Mansell J, Elliott TE (1996) *Active Support Measure*, Tizard Centre, University of Kent, Canterbury.

Mansell J, Beadle-Brown J, Ashman B, Ockendon J (2005) *Person-Centred Active Support*, Pavilion Publishing, Brighton.

Mansell J, Beadle-Brown J, Whelton R, Beckett C, Hutchinson A (2008) Effect of service structure and organisation on staff care practices in small community homes for people with intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities*, 21, 3, 398–413.

McDowell I (2006) *Measuring Health: A Guide to Rating Scales and Questionnaires*, Oxford University Press, Oxford.

McKee K, Philp I, Lamura G, Prouskas C, Öberg B, Krevers B, Spazzafumo L, Bien B, Parker C, Nolan MR, Szczerbinska K (2003) The COPE index – A first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people, *Aging and Mental Health*, 7, 39–52.

Mead N, Lester H, Chew-Graham C, Gask L, Bower P (2010) Effects of befriending on depressive symptoms and distress: systematic review and meta-analysis, *British Journal of Psychiatry*, 196, 96–101.

Overview of outcome measurement for adults using social care services and support

Miller E, Cooper SA, Cook A, Petch A (2008) Outcomes Important to people with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 5, 3, 150–158.

Moos R, Lemke S (1984) *Multiphasic Environmental Assessment Procedure (MEAP) Manual*, Social Ecology Laboratory, Stanford University, Palo Alto, California.

Moos R, Lemke S (1992) *Sheltered Care Environment Scale Manual*, Center for Health Care Evaluation, Department of Veterans Affairs and Stanford University Medical Centers, Palo Alto, California.

Morris J, Fries B, Mehr D, Hawes C, Phillips C, Mor V, Lipsitz L (1994) MDS Cognitive Performance Scale, *Journal of Gerontology: Medical Science*, 49, 4, M174–M182.

Morris J, Fries B, Steel K, Ikegami N, Bernabei R, Carpenter GI, Gilgen R, Hirdes JP, Topinková E (1997) Comprehensive clinical assessment in community setting: applicability of the MDS-HC, *Journal of the American Geriatrics Society*, 45, 8, 1017–1024.

Mozley C, Huxley P, Sutcliffe C, Bagley H, Burns A, Challis D, Cordingley L (1999) Not knowing where I am doesn't mean I don't know what I like: cognitive impairment and quality of life responses in elderly people, *International Journal of Geriatric Psychiatry*, 14, 776–783.

Mozley C, Sutcliffe C, Bagley H, Cordingley L, Challis D, Huxley P, Burns A (2004) *Towards Quality Care: Outcomes for Older People in Care Homes*, Ashgate, Aldershot.

Netten A, Forder J (2008) *Measuring the Outputs of Information & Advice Services: Initial Report*, PSSRU Discussion Paper No. 2543/2, Personal Social Services Research Unit, University of Kent, Canterbury.

Netten A, Ryan M, Smith P, Skatun D, Healey A, Knapp M, Wykes T (2002) *Development of a Measure of Social Care Outcome for Older People*, PSSRU Discussion Paper 1690/2, University of Kent, Canterbury.

Netten A, Malley J, Towers AM, Forder J, Dennett J (2008) *Outcomes of Social Care for Adults (OSCA): Outline of a research project funded by Health Technology Assessment (HTA) NIHR*, PSSRU Project Outline No. P81, Personal Social Services Research Unit, University of Kent, Canterbury.

Netten A, Burge P, Malley J, Potoglou D, Brazier J, Flynn T, Forder J (2009) *Outcomes of Social Care for Adults (OSCA): Interim Findings*, PSSRU Discussion Paper No 2648/2, Personal Social Services Research Unit, University of Kent, Canterbury.

Netten A, Forder J, Beadle-Brown J, Caiels J, Malley J, Smith N, Trukeschitz B, Towers A, Welsh E, Windle K (2010a) *Adult Social Care Outcomes Toolkit v1.0: Main Guidance*, PSSRU Discussion Paper No. 2716, Personal Social Services Research Unit, University of Kent, Canterbury.

Overview of outcome measurement for adults using social care services and support

Netten A, Beadle-Brown J, Trukeschitz B, Towers AM, Welch E, Forder J, Smith J, Alden E (2010b) *Measuring the Outcomes of Care Homes*, PSSRU Discussion Paper No. 2696/2, Personal Social Services Research Unit, University of Kent, Canterbury.

Netten A, Burge P, Malley J, Potoglou D, Towers A, Brazier J, Flynn T, Forder J, Wall B. (forthcoming) *Outcomes of Social Care for Adults: Developing a Preference Weighted Measure*, NIHR Health Technology Assessment Programme, London.

Nolan M, Davies S, Brown J (2009) Transitions in care homes: towards relationship-centred care using the 'Senses Framework', *Quality in Ageing and Older Adults*, 7, 3, 5–14.

O'Boyle A, Browne J, Hickey A, McGee H, Joyce J (1995) *Administration Manual*, Department of Psychology, Royal College of Surgeons of Ireland, Dublin.

Patterson A, Veestra G (2010) Loneliness and risk of mortality: A longitudinal investigation in Alameda County, California, *Social Science & Medicine*, 71, 181–186.

Qureshi H, Patmore C, Nicholas E, Bamford C (1998) *Outcomes in Community Care Practice. Overview: Outcomes of Social Care for Older People and Carers*, Social Policy Research Unit, University of York, York.

Qureshi H, Nicholas E (2001) A new conception of social care outcomes and its practical use in assessment with older people, *Research, Policy and Planning*, 19, 2, 11–25.

Reed J (2007) *Quality of life, My Home Life: Quality of Life in Care Homes*, Help the Aged, London.

Remington M, Tyrer P (1979) The Social Functioning Schedule – a brief semi-structured interview, *Social Psychiatry*, 14, 151–157.

Roick C, Thierfelder K, Heider D, Klemm T, Paschke R, Angermeyer MC (2004) Quality of life instruments and health state preferences to assess effects of medical interventions for mentally and medically ill patients, *Psychiatrische Praxis*, 31, 3, 128–137.

Ruta D, Garratt A, Leng M, Russell I, MacDonald L (1994) A new approach to the measurement of quality of life: the patient generated index (PGI), *Medical Care*, 32, 11, 1109–1126.

Rutter M, Tizard J, Whitmore J (1970) *Education, Health and Behaviour*, Longman, London.

Ryan M, Netten A, Skatun D, Smith P (2006) Using discrete choice experiments to estimate a preference-based measure of outcome – An application to social care for older people, *Journal of Health Economics*, 25, 927–944.

Schalock RL (ed.) (1996) *Quality of Life: Volume 1 – Conceptualization and Measurement*, American Association on Mental Retardation, Washington, D.C.

Overview of outcome measurement for adults using social care services and support

Schalock RL (2004) The concept of quality of life: what we know and do not know, *Journal of Intellectual Disability Research*, 48, 203–216.

Schwartz CE, Rapkin BD (2004) Reconsidering the psychometrics of quality of life assessments in light of response shift and appraisal, *Health and Quality of Life Outcomes*, 2, 16, 1–11.

Sen A (1985) Well-being, agency and freedom, The Dewey Lectures 1984, *The Journal of Philosophy*, 82, 4, 169–224.

Shaw I (1984) Consumer evaluations of the personal social services, *British Journal of Social Work*, 4, 277–284.

Smith S, Lamping D, Banerjee S, Harwood R, Foley B, Smith P, Cook J, Murray J, Prince M, Levin E, Mann A, Knapp M (2007) Development of a new measure of health-related quality of life for people with dementia: DEMQOL, *Psychological Medicine*, 37, 737–746.

Smith N, Netten A, Holder J, Fox D (2009) *Carers' Experiences and Outcomes: The 2008 Kent Carers Survey*, PSSRU Discussion Paper No. 2652, Personal Social Services Research Unit, University of Kent, Canterbury.

Smith N, Netten A, Holder J, Fox D (2010) *The Experience of Carers in Kent: A Comparison of the 2008 Kent Carers' Survey and the 2009/10 Carers' Experience Survey*, PSSRU Discussion Paper No. 2737, Personal Social Services Research Unit, University of Kent, Canterbury.

Stancliffe RJ, Harman AD, Toogood S, McVilly KR (2007) Australian implementation and evaluation of active support, *Journal of Applied Research in Intellectual Disabilities*, 20, 3, 211–227.

Stancliffe RJ, Jones E, Mansell J, Lowe K (2008) Active support: a critical review and commentary, *Journal of Intellectual & Developmental Disability*, 33, 3, 196–214.

The Information Centre (2010) <http://www.ic.nhs.uk/>

Twigg J, Atkin K, Perring C (1990) *Carers and Services: A Review of Research*, HMSO, London (Social Policy Research Unit).

Twining C (1991) Quality of life assessment and improvement, in Denham MJ (ed.) *Care of the Long Stay Elderly Patient*, Chapman Hall, London.

Visser-Meily J, Post M, Riphagen I, Lindeman E (2004) Measures used to assess burden among caregivers of stroke patients: a review, *Clinical Rehabilitation*, 18, 6, 601–623.

Ware JE, Snow KK, Kosinski M, Gandek B (1997) *SF-36 Health Survey, Manual & Interpretation Guide. 2nd ed: (MOS 20) Social Functioning Subscale*, The Health Institute, New England Medical Center Boston.

Overview of outcome measurement for adults using social care services and support

Williams A (1991) Is the QALY a technical solution to a political problem? Of course not, *International Journal of Health Services*, 21, 365–369.

Windle K, Wagland R, Forder J, D'Amico F, Wistow G (2009) *National Evaluation of Partnerships for Older People Projects: Final Report*, PSSRU Discussion Paper No. 2700, Personal Social Services Research Unit, University of Kent, Canterbury.

Windle K, Caiels J, Netten A, Masrani R, Welch E, Forder J (2010) *Measuring Outcomes of Information and Advice Services: Final Report*, PSSRU Discussion Paper No. 2713, Personal Social Services Research Unit, University of Kent, Canterbury.