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Measuring the outcomes of low-level services: Annexes to final report

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Measuring the outcomes of low-level services: Annexes to final report

This document serves as a supplement to the low level interventions report (PSSRU Discussion Paper 2699) and is presented as a working reference document to accompany the main report. All Annexes are referred to in the main report with the exception of Annex nine. Annex nine is an additional paper which provides further context to the background of the study. It places the study in terms of its theoretical standpoint and provides more detail regarding the conceptualisation of measurement from an outcomes-based perspective.

Annex 1 – Preventative Services

Prevention is a term that is used increasingly frequently within health and social care services and policy, however there is no clear-cut definition and no consensus as to what constitutes 'preventive services'. Compounding this lack of clarity is a further haziness around the boundary between health and social care and between social care and wider community services such as housing and transport. Prevention as a concept refers to upstream interventions which seek to help people maintain or improve health before it is compromised. This stands in contrast to the traditional role of the health care system that is to restore health once it has already come under threat(Health Canada, 2002).

Prevention has different meanings in different contexts (Godfrey, 2001). If a narrow perspective is taken, a preventive service may be said to be one that aims to prevent or delay a specific condition or outcome. An example could be a service that aims to prevent admission to hospital because of a fall. This type of service has a clear remit with a well-defined outcome. However, it is widely accepted that prevention as a concept is significantly more inclusive, and that the concepts of quality of life, independence and control are central to the prevention agenda.

Focusing on older people, Godfrey locates prevention within a theoretical model of 'successful ageing'. This conceptualises ageing as involving adaptation to the changing balance between gains and losses over the life course. 'Successful ageing is perceived as the attainment of valued goals, the minimisation of losses and maximisation of gains through the linked processes of selective compensation and optimisation' (Godfrey, 2001, p. 89). Within this model, preventive services may be conceived as resources to be drawn upon to support compensatory strategies. Similarly, outcomes and effectiveness of services may be evaluated in terms of whether they facilitate / allow older people to achieve valued goals. Godfrey (ibid) argues that in developing and evaluating preventive services in social care, the question of interest should be reformulated to: 'what contribution do specific services make in optimising gains and compensating for the losses that accompany ageing?'

Wistow and Lewis's (1997) influential conception of prevention encompassed the following three wide-ranging aims:

- to prevent or delay ill health or disability consequent upon ageing;
- to promote/improve quality of life of older people, their independence and inclusion in social and community life;
- to create healthy and supportive environments.

The latter two points underline the broad nature of preventive services and the role that they are seen to play in promoting social inclusion which, in itself, is seen to be key to maintaining good health and independence (Wistow, Waddington, & Godfrey, 2003).

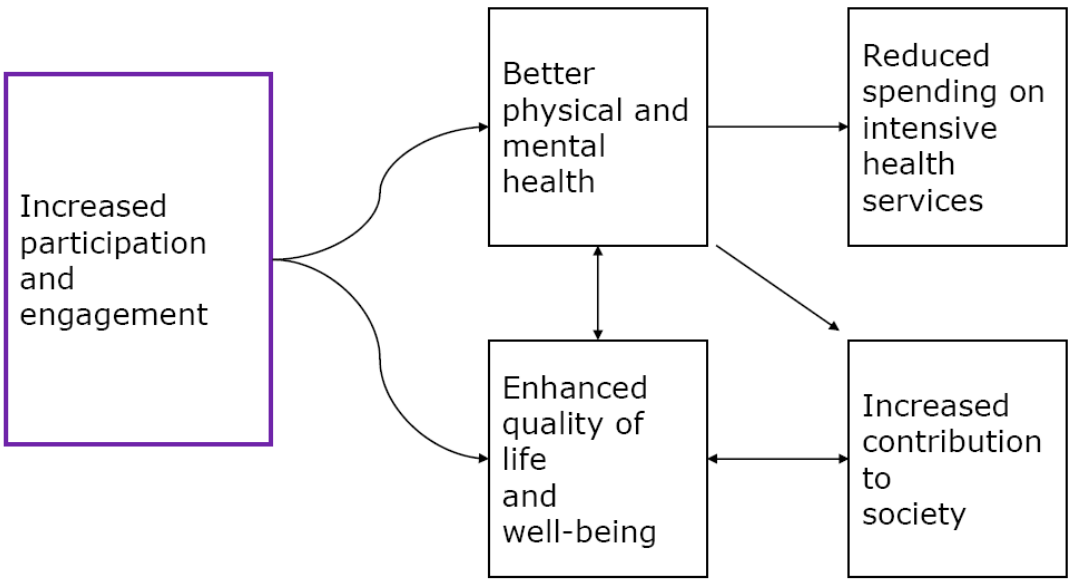
An alternative, but similar, definition has been put forward in recent work by the Social Exclusion Unit (2005). This concept of prevention is more explicit in its intention to reduce current resource consumption and also carries forward the idea that prevention is a holistic concept that recognises the centrality of social inclusion and social engagement in good health. The implication is that if we can maintain good health, through the means of prevention, then the need for more costly services

will be reduced or delayed or, in some cases, even prevented (Office of the Deputy Prime Minister, 2006). As such, the ODPM uses the following two elements to describe preventive services:

- services that prevent/delay the need for more costly intensive services;
- services that promote the quality of life of older people and their engagement with the community.

Further to this the ODPM put forward 'a simple model' outlining the rationale for preventive services and the ways in which preventive services can benefit older people (see Figure 1). According to the ODPM, some low-level services such as home adaptations, falls prevention and Warm Front (a scheme intended to reduce fuel poverty) can result in direct health benefits, leading to reduced expenditure on intensive health services. Additionally, increased activity and social engagement can lead to a self-reinforcing cycle of enhanced quality of life and wellbeing, enabling older people to make an increased (mutually beneficial) contribution to society.

Figure 1



Source: ODPM, 2006

The concept of preventive services is underpinned by two major assumptions. Firstly, that ultimately they will result in lower use of resources, and will consequently prove cost-effective long term, and secondly that preventive services have a role to play in improving quality of life and promoting independence and wellbeing. Both of these assumptions are held up by government policy. Low-level interventions are inexorably linked with the concept of preventive services, however definitional issues abound in the literature and it is to these that we will now turn to.

Low level interventions – definition

Low level interventions as a concept generally refers to upstream interventions which seek to help maintain or improve health before it is compromised. The implication is that if we can maintain good health, through the means of prevention, then the need for more costly services will be reduced or

delayed or, in some cases, even prevented (Office of the Deputy Prime Minister, 2006). In general, low level or low intensity interventions are those services or initiatives that require minimal resource input in terms of working hours and do not necessarily require the input of specialists (Curry, 2006).

The underlying rationale for low level interventions is essentially the same as all preventative care – that investment now will yield future savings. It has frequently been preventative services (particularly low level interventions) that have been squeezed as resources have been moved to focus on acute, high need cases (Godfrey, 1999). It could be argued that this is a false economy, as individuals who require just a low level of assistance to live independently would, without provision of this assistance, more quickly require high intensity and high cost care. Intervening early, or in a timely manner, is intended to delay, and even reduce the intensity of this need. However, installing a hand rail in someone's home or providing them with help to go shopping twice a week requires financial commitment, so it is necessary to prove that, ultimately, the long-term economics of shifting resources to this end of the care spectrum are robust. The challenge, clearly, is establishing the link between the implementation of a given intervention and the outcome achieved. Hitherto standard measures for functioning states have not been developed.

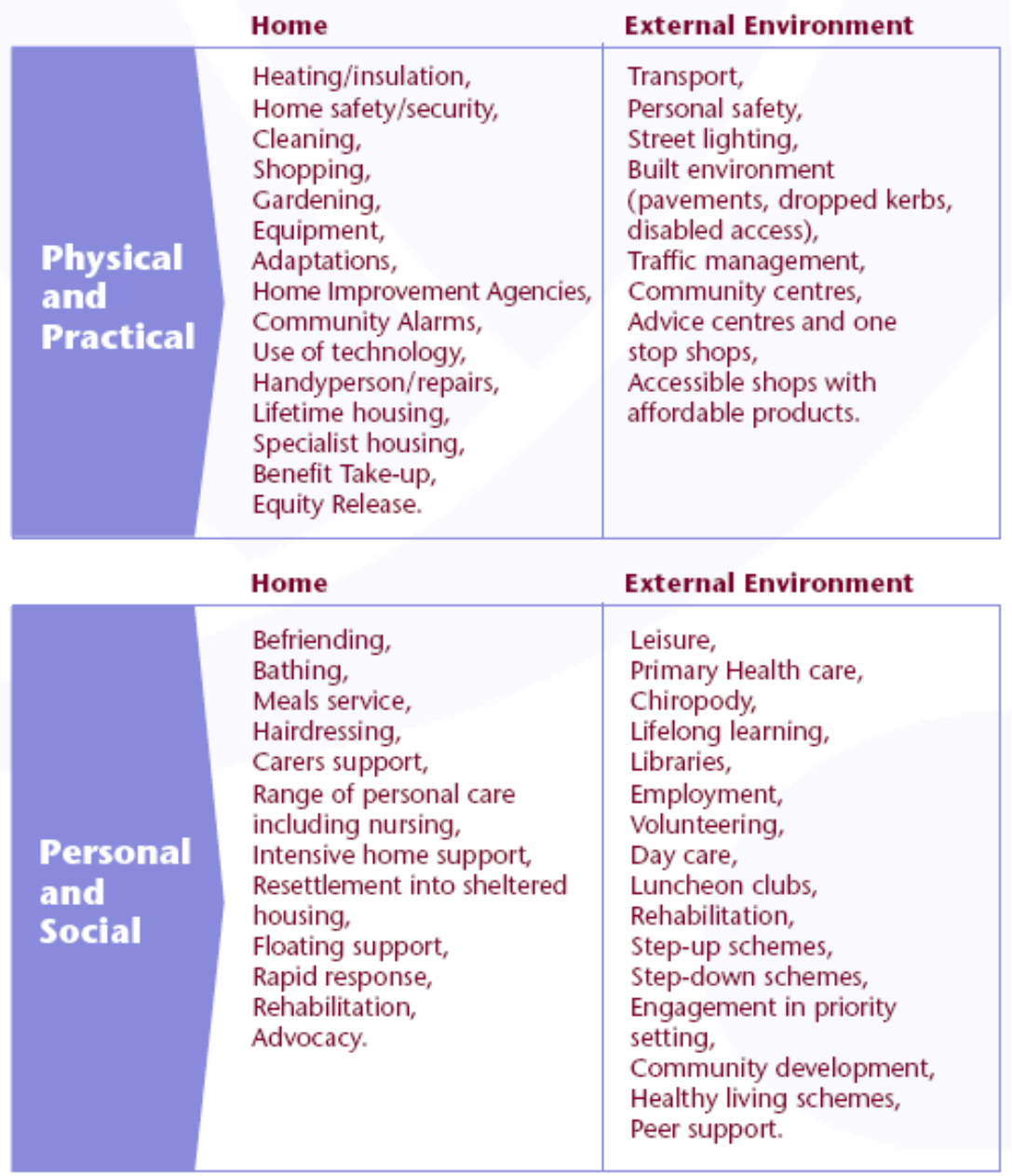
It is argued by a number of commentators (Billis & Glennerster, 1998; Clark, Dyer, & Horwood, 1998; Elkan et al., 2001; Godfrey, 1999; Quilgars, 2000; Wistow et al., 2003) that a low-level of assistance in such areas of everyday life can enhance quality of life through enabling an older person to remain in their own home, maintain independence and reduce the risk of institutionalisation. Godfrey, for instance, argues that relatively minor alterations and help can be the difference between someone living independently in the community and being admitted to hospital or a care home and, as such, are critical to maintaining quality of life (Godfrey, 1999). Although it is generally recognised that such low-level services, alone, cannot prevent ultimate deterioration in health, they *may* be able to delay this deterioration and thus delay admission to a care home (Audit Commission, 2004).

What services?

A broad range of services and initiatives may be considered 'low-level' although no standard definition appears to exist. Examples of such services that might be classed as low-level include help with those tasks that people find difficult as they get older, such as gardening, laundry, cleaning and shopping (Clark et al., 1998). Another tier of 'low-level' interventions includes home adaptations, such as the installation of handrails and ramps.

One of the most comprehensive illustrations of what constitutes a low-level intervention is provided by the Social Exclusion Unit (Social Exclusion Unit, 2005) adapted from the Joseph Rowntree Foundation (2003). This model distinguishes between physical and practical low-level services in both the home and the external environment, and personal and social low-level services in the home and the external environment (see Figure 2).

Figure 2. Perceived benefits of low level interventions



Source: Social Exclusion Unit, 2005

There is something of a dearth of evidence regarding the cost-effectiveness of low-level interventions, particularly studies that quantify the impact of low-level interventions in terms of the functioning states they hope to achieve. Despite this lack of quantitative evidence, there is a bank of qualitative work that endorses the value of low-level interventions, particularly for older people. In 'That bit of help' Clark et al. (1998) argue that low-level interventions are key to maintaining independence, avoiding institutionalisation and reducing isolation.

Research conducted on behalf of the Joseph Rowntree Foundation's Older People's Inquiry(Joseph Rowntree Foundation, 2005) identified a 'baker's dozen' of low level supports that older people valued because they enabled them to stay in their own homes. These initiatives, such as a 'handy help' - a scheme for small repairs around the house, 'welcome home' – a scheme for those returning from hospital, and 'sole mates' – which provides a foot bath and toe nail clipping service, are all held up as examples of services that improve the quality of life of older people and help maintain their independence. The research also identified a number of themes that older people considered important in terms of maintaining independence, these were:

- comfortable and secure homes;
- an adequate income;
- safe neighbourhoods;
- the ability to get out and about;
- friendships;
- learning and leisure;
- keeping active and healthy;
- good, relevant information.

In addition to practical help that can be provided by low-level interventions, The House of Lords Select Committee on Science and Technology (House of Lords Select Committee on Science and Technology, 2005, p. 53) emphasise the importance of services and initiatives that enhance mental health and general wellbeing. They found that 'inactivity and isolation accelerate physical and psychological decline, creating a negative spiral towards premature, preventable ill health and dependency.' Thus, initiatives such as befriending schemes that enable older people to maintain control, dignity and independence and, in doing so, reduce or delay the need for high intensity health and social care services (Clark et al., 1998) are important aspects of maintaining a sense of social inclusion and good mental health. Work by Layard (2005) also emphasises the importance of happiness in maintaining an effective economic, health and social care system.

The cost effectiveness of services that promote happiness, independence and general wellbeing is difficult to establish. However, there has been some attempt to quantify isolated schemes. One intervention that has been widely implemented across the country is the Sloppy Slippers Campaign which aims to highlight the risks of ill-fitting slippers and encourages older people to exchange old, ill-fitting slippers for new ones that fit. The basis for this scheme is that, of the 300,000 older people who go to hospital with serious injuries from falling, around 9 per cent blame their slippers (Department of Health, 2003). It is estimated that the Sloppy Slippers Campaign reduced falls by 32 per cent in the first year and 37 per cent in the second year. If this were rolled out across the country, it is estimated that some £500 million could be saved in terms of reduced falls and the resulting treatment required (Office of the Deputy Prime Minister, 2006).

Day care services and Quality of Life

How to fill in the questionnaire

Please fill in this questionnaire using **black biro**.

1. Most questions on the following pages can be answered simply by putting a cross in the box next to the answer that applies to you, like this:

Yes ☒

No ☐

2. Arrow symbols → are used to guide you to the questions we would like you to answer.

Yes ☒ → **GO TO Q2**

No ☐ → **GO TO Q4**

If there are no arrow symbols, please go to the next question.

3. If you change your mind about an answer you have given, completely block out the box you have crossed [■] and then put a cross in your preferred answer box.

Section 1: About yourself

This group of questions will help us to get a picture of the types of people who took part in this survey.

1. How old are you? _____ years.

***2.* Are you male or female?** *Please cross one box only* ☒

Male ☐

Female ☐

***3.* Do you live on your own?** *Please cross one box only* ☒

Yes ☐

No ☐

Section 2: About your health and support needs

The questions in this section ask about your health at the moment and the support that you get.

***4.* Please look at the following activities and say what you can do on your own and what you need help with.**

Please cross one box in each line ☒

Do you usually manage to:	On your own without help	On your own with difficulty	Not at all on your own
Get dressed or undressed	☐	☐	☐
Get in and out of bed or a chair	☐	☐	☐
Wash your face and hands	☐	☐	☐
Prepare hot meals	☐	☐	☐
Walking at least 10 minutes	☐	☐	☐

5. Do you get any help with these activities from family members, neighbours or friends?

Please cross one box only ☒

Yes ☐→ **GO TO Q6**

No ☐ → **GO TO Q7**

6. **Do you live with this person?** *Please cross one box only* ☒

Yes ☐

No ☐

7. Do you deal with your finances and paperwork - for example, paying bills, writing letters - by yourself?

Please cross one box only ☒

Yes ☐ → **GO TO Q10**

No ☐ → **GO TO Q8**

8. **Could you if you had to?** *Please cross one box only* ☒

Yes ☐

No ☐

9. **Does someone do this for you?** *Please cross one box only* ☒

Yes ☐

No ☐

10. Do you get any help or support from family members, neighbours or friends with practical tasks such as shopping, cleaning or gardening?

Please cross one box only ☒

Yes ☐

No ☐

Don't Know ☐

11. Do you have any aids or equipment that help you to manage in your home? *Please cross one box only* ☒

Yes ☐

No ☐

12. Have you used or visited any of the following services in the last three months?

Please cross either Yes or No for each statement ☒

	YES	NO
Local authority arranged home care or home help	☐	☐
Privately arranged home care or home help	☐	☐
Lunch club	☐	☐
Meals on wheels	☐	☐
Dial-a-Ride or other transport service	☐	☐
District nurse, health visitor or other nurse	☐	☐
Occupational therapist, physiotherapist, speech or other therapist	☐	☐
Stayed overnight in hospital	☐	☐
Social worker or care manager	☐	☐

Section 3: About your lifestyle and quality of life

The following questions are about how you feel at the moment about aspects of your life and home. For each question, please tick the box that comes closest to describing how you feel.

13. Thinking about your home, which of the following statements best describes your present situation?

Please cross one box only ☒

My home is as clean and comfortable as I want ☐

My home is less clean and comfortable than I want ☐

My home is not at all as clean or comfortable as I want ☐

14. Which of the following statements best describes how safe you feel? *Please cross one box only* ☒

Not feeling safe could be due to fear of abuse, falling or other accidental physical harm, and fear of being attacked or robbed.

I feel as safe as I want ☐

Sometimes I do not feel as safe as I want ☐

I never feel as safe as I want ☐

15. Thinking about the meals you eat, which of the following statements best describes your present situation? *Please cross one box only* ☒

I eat the meals I like when I want ☐

I don't always eat the right meals I want, but I don't think there is a risk to my health ☐

I don't always eat the right meals I want, and I think there is a risk to my health ☐

16. Thinking about the way you look and feel, which of the following statements best describes your present situation? *Please cross one box only* ☒

I feel clean and wear what I want ☐

I sometimes feel less clean than I want or sometimes can't wear what I want ☐

I feel much less clean than I want, with poor personal hygiene ☐

17. Thinking about your usual activities including leisure, doing things for others and paid or unpaid employment, which of the following best describes your present situation? *Please cross one box only* ☒

I do the activities I want to do ☐

I do some of the activities I want to do ☐

I don't do any of the activities I want to do ☐

Many people value being in control of their daily lives and having independence.

By 'control over daily life' we mean you are the one making decisions about your life, and having the choice to do what you want, when you want.

18. Which of these statements best describes your present situation? *Please cross one box only* ☒

I have as much control over my daily life as I want	☐
Sometimes I don't feel I have as much control over my daily life as I want	☐
I have no control over my daily life	☐

19. **Which of the following statements best describes your social situation?** *Please cross one box only* ☒

By social situation we mean keeping in touch with people and spending time with people that you want to be with.

My social situation and relationships are as good as I want	☐
Sometimes I feel my social situation and relationships are not as good as I want	☐
I feel socially isolated and often feel lonely	☐

20. Which of these statements best describes how worried or concerned you feel? *Please cross one box only* ☒

I feel free from worry and concerns on a day-to-day basis	☐
I sometimes feel worried and concerned	☐
I feel very worried and concerned on a daily basis	☐

21. Which of the following best describes your present situation?

Please cross one box only ☒

I am treated by other people with the dignity and respect that I want	☐
Sometimes I am not treated by other people with the dignity and respect that I want	☐
I am never treated with the dignity and respect that I want	☐

Finally, we are also interested in speaking to some people in more detail about day care services and the support that they receive. This will involve a researcher from BMRB Social research coming into your home to speak to you directly about your experiences. All of your answers will remain confidential and it is likely to take about one hour.

22. Would you be happy for a researcher from BMRB to contact you? *Please cross one box only* ☒

Yes – happy to be contacted → GO TO Q23	☐
No – please do not contact me → END OF QUESTIONNAIRE	☐

23. Please could you enter your full name e.g. Mrs Jane Brown?

……

24. Please could you enter your full address including postcode?

……

……

……

25. Please could you enter your telephone number (including area code) so we can phone you to arrange a suitable time to call at your address?

……

This is the end of the survey
Thank you very much for taking part.

Please now send the questionnaire back to us in the envelope provided. You do not need a stamp. Please return your questionnaire by (?) 2008.

Annex 3 – Cognitive interviews (raw data) round 1

Low Level Service ASCOT questions – notes from cognitive testing

Meals and nutrition

Thinking about the meals you eat, which of the following statements best describes your present situation?

Please tick (✓) one box

I eat what I regard as the right meals for me at times suited to me	
I do not always eat the right meals, but I don't think there is a risk to my health	
I do not always eat the right meals, and I think there is a risk to my health	

People were able to answer this question but there may be some under-reporting of need due to people being unsure as to what is meant by 'risk to health.' One participant described how he had been told by doctors to lose weight and alter his diet due to risk of diabetes but still did not answer at the bottom level. However this form of the question seems to have worked well in other work (ibsen, UES etc) Other comments were that the options were difficult to read.

Suggested change (Q1)

Thinking about the meals you eat, which of the following statements best describes your present situation?

Please tick (✓) one box

I am able to eat the meals I like when I want	
I don't always eat the right meals, but I don't think there is a risk to my health	
I don't always eat the right meals, and I think there is a risk to my health	

Do the services that you use or receive help you eat enough food that is suitable?

Please tick (✓) one box

Yes	
No	
Don't know	

This question worked well but there was confusion as to what exactly was meant by the term 'services' (see below).

Suggested change (Q2)

Do the day care services that you use help you to eat enough food that is suitable for you?

Please tick (✓) one box

Yes	

No	
Don't know	

If you did not get the help that you do from the services you use, and other help did not step in, which of the following statements do you think would best describe your situation?

Please tick (✓) one box

I would eat what I regard as the right meals for me at times suited to me	
I would not always eat the right meals, but I don"t think there would be a risk to my health	
I would not always eat the right meals, and I think there would be a risk to my health	

This question format worked well, people understood what it was asking and could make the hypothetical jump to imagining life without services. However participants' interpretation of 'services' was problematic throughout and many interpreted services as 'all the help you get from everyone.' Participants included friends/family/church while others were unsure whether it included day care centre at all. As we are now focussing on day care we might want to replace 'services' with 'day care' or 'day care services.'

Suggested change (Q3)

If you did not get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation?

Please tick (✓) one box

I would be able to eat the meals I like when I want	
I would not always eat the right meals, but I don't think there would be a risk to my health	
I would not always eat the right meals, and I think there would be a risk to my health	

Accommodation cleanliness and order

Thinking about your home, which of the following statements best describes your present situation?

Please tick (✓) one box

My home is clean and comfortable	
My home is quite clean and comfortable	
My home is not at all clean **or** comfortable	

This question worked ok for most participants. Some were confused by the difference between the first two options (i.e. difference between 'clean' and 'quite clean') and did not know which one was the more desirable (top) option.

Suggested change (Q4)

Thinking about your home, which of the following statements best describes your present situation?

Please tick (✓) one box

My home is clean and comfortable	
My home could be more clean and comfortable than it is	
My home is not at all clean **or** comfortable	

Personal safety

Feelings of safety could be due to fear of abuse, falling or other accidental physical harm, and fear of being attacked or robbed.

Which of the following statements best describes how safe you feel?

Please tick (✓) one box

I feel safe	
Sometimes I do not feel safe	
I never feel safe	

This seemed to work well. Participants found the options easy to understand due to being short and easy to read.

Interpretation: most participants related safety to feeling safe in their homes (locking doors at night etc) but also understood the other aspects of safety as explained in the question. One person said they would not go out after dark as they had no need to, but thought that they would feel unsafe if they did.

No suggested change (Q5) continue testing in second round

Personal cleanliness and comfort

Thinking about the way you look and feel, which of the following statements best describes your present situation?

Please tick (✓) one box

I feel clean and able to wear what I want	
I occasionally feel less clean than I would like or am not able to wear what I want	
I feel much less clean than I would like	

This question worked well.

No suggested change (Q6) discontinue testing in second round.

Social participation and involvement (social well-being)

(a) Which of the following statements best describes your social situation?

– by social situation we mean keeping in touch with people and spending time with people that you want to be with.

Please tick (✓) one box

I have a good social situation	
I have good relationships with people but I sometimes feel lonely	
I often feel lonely	

7 (b) Which of the following statements best describes your social situation?

– by social situation we mean spending time with people that you want to be with.

Please tick (✓) one box

I have good relationships and spend time with people that I want to be with as much as I want	
I have good relationships with people and spend time with people that I want to be with, but not as much as I want	
I don't have any good relationships **or** I don't spend time with people	

(c) Which of the following statements best describes your social situation?

– by social situation we mean keeping in touch with people and spending time with people that you want to be with.

Please tick (✓) one box

I am happy with my social situation	
I don"t have good relationships **or** I do not spend time with people as often as I would like	
I do not spend time in the company of others and I often feel lonely	

All the above versions of the social well-being question were tested in separate interviews.

Interpretation: The definition of 'social situation' worked well. Participants interpreted social situation as spending time with friends and family and keeping in touch with people (this could be by phone for those who were long distance).

Question 7(c) worked best on balance as people who were 'not social people' but were happy with their situation could answer with the top option.

The social well-being question from the carers work is about to be tested. A possibility for the second round is to test this with Q7c and ditch versions (a) and (b).

Suggested addition (from carers work) (Q7)

Which of the following statements best describes your present situation?

I am happy with my social situation	
Sometimes I feel lonely or cut off from others	
I feel socially isolated or often feel lonely	

Plus Continue testing Q7c in second round

Occupation (inc. role support): leisure

Which of the following statements best describes your present situation with respect to your leisure activities?

This can include any interests, hobbies, pastimes, entertainment and so on.

Please tick (✓) one box

I do the things I want to do	
I do some of the things I want to do	
I don't do any of the things I want to do	

This question worked well and participants were happy with the definition of 'leisure' as well as the options given. However the second part of the question (purposeful activities) did not work well and so we may need to consider combining these and changing the definition to include these (purposeful) activities.

See below for suggested change combining both occupation (leisure and purposeful) questions

Do any services that you use or receive help you to do the things you want to do?

- **Such as by enabling you to take a break, or leave the house, or save you time that you can spend doing other activities?**

Please tick (✓) one box

Yes	
No	
Don"t know	
Not applicable	

Some interpretation issues: some participants interpreted 'take a break' as meaning a holiday while others thought it meant taking a break from a specific task (e.g. doing washing). Also one participant interpreted 'saving time to do other activities' as coming in and

taking over what they did around the house and shopping etc (which they wanted to do and gave them purpose) and simply doing it quicker. In this case the participant said it would leave them with nothing to do and would result in them being bored. Some participants found the bullet point confusing in terms of what the question was asking them.

Suggested changes: specify day care services, delete explanation / expansion of question and delete 'not applicable' option.

Do any of the day care services that you use help you to do the things you want to do?

Please tick (✓) one box

Yes	
No	
Don"t know	

If you did not get the help that you do from services that you use or receive, and other help did not step in, which of the following statements do you think would best describe how you would spend your time?

Please tick (✓) one box

I would do the things I want to do	
I would do some of the things I want to do	
I would not do any of the things I want to do	

This question worked well. Suggest changing 'services' to specify 'day care services'

Occupation: purposeful activities

Which of the following statements best describes your present situation with respect to any purposeful activities, like work, caring for others, voluntary activity, spiritual activities and other things like this?

Please tick (✓) one box

I do the things I want to do	☐
I do some of the things I want to do	☐
I don't do any of the things I want to do	☐

This question was problematic. Almost all participants felt it did not apply to them with the exception of one who went to church. We assumed that some users would also be carers (and indeed many might be) but this did not apply to any of those interviewed.

Suggested change: combine occupation – as below

Do any services that you use or receive help you to do the things you want to do?

- **Such as by enabling you to take a break, or leave the house, or save you time that you can spend doing other activities?**

Please tick (✓) one box

Yes	☐

No	
Don"t know	
Not applicable	

Comments as above. See suggested change (above)

If you did not get the help that you do from services that you use or receive, and other help did not step in, which of the following statements do you think would best describe how you would spend your time on things like work, caring for others, voluntary activities, spiritual activities and other things like this?

Please tick (✓) one box

I often undertake purposeful activities (compared to people in general)	
I sometimes undertake some purposeful activities	
I am mostly do not undertake purposeful activities	

The term 'purposeful' was extremely problematic. Participants did not know what was meant by this and felt it did not apply to them. Participants did not know who 'compared to people in general' referred to and therefore had difficulty answering.

Suggested change for occupation (combined):

Thinking about your usual activities including leisure, doing things for others and paid or unpaid employment, which of the following statements best describes how you spend your time?

Please tick (✓) one box

I do the things I want to do	

I do some of the things I want to do	
I don"t do any of the things I want to do	

Do any of the day care services that you use help you to do the things you want to do?

Please tick (✓) one box

Yes	
No	
Don't know	

Control over daily life

Being in control of your daily life, and being the one who makes decisions about things, or having things done for you when you want them done, and being independent are important to many people.

By 'control over daily life' we mean you are the one making decisions about your life, such as when and where you do the things that you want to do.

Could you tell me which of these statements best describes your present situation with regard to having control over your daily life?

Please tick (✓) one box

I feel in control of my daily life	
I have some control over my daily life	

I have no control over my daily life ☐

This question worked well. Participants understood the question and the definition of control over daily life.

No suggested changes – continue testing in round 2

Anxiety and worry

Could you tell me which of these statements best describes your present situation with regard to feelings of worry or anxiety?

Please tick (✓) one box

I feel free from worry and anxiety on a day-to-day basis ☐

I sometimes feel anxious and worried ☐

I feel very anxious and worried on a daily basis ☐

This question worked reasonably well. Some participants felt it was a bit difficult to read and one thought it was better to have 'concern' rather than anxious.

Interpretation: participants related feelings of anxiety to health and financial situation.

Suggested change (Q15)

Could you tell me which of these statements best describes how anxious or worried you feel?

Please tick (✓) one box

I feel free from worry and anxiety on a day-to-day basis ☐

I sometimes feel anxious and worried	
I feel very anxious and worried on a daily basis	

Do the services that you use or receive help you to feel less anxious or worried about your daily life?

Please tick (✓) one box

Yes	
No	
Don"t know	

As before - problem with term 'services'. Suggest changing to 'day care services'.

If you did not get the help that you do from the services you use, and other help did not step in, which of the following statements do you think would best describe your situation?

Please tick (✓) one box

I would feel free of worry and anxiety on a day-to-day basis	
I would sometimes feel anxious and worried	
I would feel very anxious and worried on a daily basis	

Comments same as previous opening anxiety question.

Suggested change

If you did not get the help that you do from the day care services you use, and other help did not step in, which of the following would best describe how anxious or worried you would feel?

Please tick (✓) one box

I would feel free of worry and anxiety on a day-to-day basis	
I would sometimes feel anxious and worried	
I would feel very anxious and worried on a daily basis	

Choice and capability

Thinking about all of these aspects of your life overall – your personal care, social life, safety, pastimes and so on – do you feel that your ability to make choices about what you want to do in your life is limited?

My choices about how I lead my life are not limited	
My choices are somewhat limited	
My choices are extremely limited in how I live my life	

This question seemed to work well for most people with one having trouble with the term 'somewhat' in the second option. One person also described how they could not do the things they used to (such as see friends etc because they were too far away) but still answered at the top level (not limited). Not sure how to resolve this. Possible addition of explanation of what we mean by 'choices'?

Suggest change ‘somewhat’ to ‘fairly’ and continue testing. Add explanation of what we mean by ‘choices’?

Do you think that services you use or receive give you more choice or less choice about how you lead your life?
Please tick (✓) one box

More choice	
Less choice	
Makes no difference	
Don‟t know	

Worked ok, especially for people commenting on services giving them ‘more choice’, although no-one said services gave them ‘less’ choice as this seemed incongruent with what ‘services’ were provided for. Would anyone would choose ‘less choice’? Under what circumstances?

Same problems with ‘services’ term.

Change ‘services’ term. Other changes?

If you did not get the help that you do from the services you use or receive, which of the following statements do you think would best describe your situation?

My choices about how I lead my life would not be limited	
My choices would be somewhat limited	
My choices would be extremely limited in how I live my life	

People understood how services made them less limited in their choices but also stated that services couldn't do anything about their physical limitations so in that sense that they would always be limited.

Changes?

What areas of your life does this mainly affect?

This question was unsuccessful and participants did not understand what it referred to and how they were supposed to respond. It is possibly too open but may work with further prompting.

Suggest change? Or perhaps delete.

Annex 4 – Mail shot letter to local authorities

Dear CSSR / Local Authority,

I am writing on behalf of the Personal Social Services Research Unit, University of Kent. We are currently involved in a research study being funded by the Treasury and led by the Office of National Statistics. The aim of the Quality Measurement Framework (QMF) programme is to create new mechanisms for more effective and efficient measurement and monitoring of third sector provision of public services. The purpose is to develop methodologies for measuring and assessing the value added of the relevant public services. They will constitute a toolkit that can be used by commissioners and providers to assess and monitor the performance of services delivered. For more details of the project see: www.ons.gov.uk/qmf.

The QMF low level services project aims to assess the outcomes and quality of non-residential social care services for older people. The main focus will be on day care services for older people funded (partly or wholly) with public funds and including private, public and third sector organisations.

The study is being overseen by Professor Julien Forder and Professor Ann Netten and has been granted full Kent County Council Research Governance approval.

We are currently compiling a sample frame from a number of sources. The aim is to establish a full list of relevant organisations providing services in the above category, by locality (local authority area or region). The sample frame will be used to select local provider units on a quasi-random basis, that is, a purposive plus randomly selected sample.

We are writing to all Councils with Social Services Responsibilities to compile a list of all day care services that local authorities currently contract to provide day care services in their local authority. This information should include the name, address and contact of the providers used. It would be of great help if you could provide us with this information and I would like to thank you in advance for your time.

If you have any queries or questions regarding the study please do not hesitate to contact me on the details below. Many thanks for your interest in the study.

Yours sincerely

James Caiels
Research Officer
Personal Social Services Research Unit
University of Kent

Tel: 01227 827552
Email: j.caiels@kent.ac.uk

Annex 5 – Interview schedule to recruit providers

Recruitment questionnaire

ASK FOR NAMED CONTACT

INTRO Good morning/afternoon, my name is _____ calling on behalf of BMRB, an independent market research organisation, for the University of Kent. We are conducting a study among older people who use the social care services offered by providers such as yourselves, and would like to ask for your help.

Do you have a few minutes to answer a couple of questions?

IF NECESSARY: This study aims to assess the outcomes of non-residential social care services for older people.

IF NECESSARY: The survey is voluntary

IF NECESSARY: We can send some advance information, and if having seen the information your organisation doesn't wish to take part, you can let us know when we send the information to you.

- Yes - Proceed
- No - THANK AND CLOSE

Q1 Can I just check, do you provide non-residential social care services for people aged 65 and over?

IF NECESSARY: This can include meals on wheels, home help, day care, etc.

INTERVIEWER NOTE: If don't know, go back and try to speak with someone who does know.

- Yes CONTINUE
- No THANK AND CLOSE

Q1a We have been passed your organisation's details from the Local Authority that you work with.

We are conducting a study to assess the outcomes of non-residential social care services for older people.

We would like to ask your organisation to help with the survey by distributing some questionnaires to older people who use your services. The questionnaire asks recipients of day care services some questions about the services they receive, and their current state of well-being.

Would you be willing to help us with the research, and hand out some short paper questionnaires to some of your clients?

IF NECESSARY: We will send out 50 short questionnaires to your organisation, and we would like you to hand these out to the first 50 service users who are aged 65 or over that you come into contact with. These people will be asked to fill out the questionnaire and return them to us using a pre-paid envelope.

IF NECESSARY: We can send some advance information, and if having seen the information your organisation doesn't wish to take part, you can let us know.

IF NECESSARY: You will not need to do anything else after you have handed the questionnaire out.

• Yes - willing to take part	1	GO TO Q6A
• Want more information	2	GO TO Q6
• Need to check internally (with someone who's not available at the moment)	3	GO TO Q2A
• Need to check with Head Office / externally	4	GO TO Q3B
• No - refuse contact details	5	GO TO Q5

IF q1 = Need to check internally ASK Q2A

Q2A I can call back when you've checked with them. When is the best time to call?

INTERVIEWER: YOU WILL BE TAKEN TO THE APPOINTMENT SCREEN

IF (q1 = Need to check with Head Office / externally)

Q3B Could we call you back once you've spoken to Head Office?

- Yes GO TO Q3C
- No GO TO Q5

IF Q3B = Yes

Q3C Thank you. When would it be best to call you back?

INTERVIEWER: YOU WILL BE TAKEN TO THE APPOINTMENT SCREEN

IF (Q1A = No) OR (Q3b = No) THEN ASK: Q5

Q5 I understand. The survey is voluntary; however we would like to speak to as many people as possible to get an idea of how people use these services and how they help them.

We do have an information letter that gives some more information about the research. Would you like me to send this letter to you?

- Yes GO TO Q6
- No THANK AND CLOSE

IF Q5 = YES OR Q1A = WANT MORE INFO

Q6 Thank you for your time. I can send an information letter to you in the post or email one over to you.

- Email – RECORD EMAIL ADDRESS (will get sent automatically via CATI system)
- Post - CHECK ADDRESS FROM SAMPLE AND AMEND IF NECESSARY

I will send over more information and call again when it might be more convenient. When would be the best time to call you back?

INTERVIEWER: YOU WILL BE TAKEN TO THE APPOINTMENT SCREEN

IF (Q1a = Yes - willing to take part)
THEN ASK: Q6A, Q6B, Q6C

Q6A Thanks very much for helping with the survey!

We would like to collect the contact details of someone who comes into contact with people aged 65 and over who use your services, so that we can send them some more information about the survey and provide them with some short questionnaires to hand out. Are you the best person to send this information to?

- Yes
- No
- Refused information

IF Q6A = 1
Firstly, can I take your title? (Mr, Miss, Mrs, Ms)
IF Q6A = 2
Please can I have the name of the best person to contact, starting with their title

ENTER TITLE

Miss
Mrs
Mr
Dr
Ms
Other specify

Q6B Can I take your/their first name?

INTERVIEWER NOTE: If reluctant to give first name, please ask for their initial

WRITE IN:

Q6C Can I take your/their last name?

WRITE IN:

Q6D Is this the correct company name [+PROVIDER NAME+]?

- Yes PROCEED
- No WRITE IN NEW NAME

QCHECK Can I check that this is the address that I should send the information to?

FILL IN FROM SAMPLE:

- Company name
- Building name or number
- 3rd line of address
- 4th line of address
- 5th line of address
- County
- Postcode

IF AMENDMENTS NEEDED THEN FILL OUT FORM

CHANGE COMPANY NAME	1
CHANGE BUILDING NAME/NUMBER	2
CHANGE THIRD LINE	3
CHANGE FOURTH LINE	4
CHANGE FIFTH LINE	5
CHANGE COUNTY	6
CHANGE POSTCODE	7
ALL OK^s	8
NEW ADDRESS^s	9

Q7 And can I just check we have the best number to get hold of you/them on, in case we need to contact you/them again?

We have [+TEL NO+].

- Yes - that's the best number 1
- No 2
- Don't Know Y

IF (Q7 = No or Don’t Know)THEN ASK: Q8

Q8 What is the best phone number for us to call?

INTERVIEWER: ENTER NEW PHONE NUMBER.

Q9 Finally, can I just check which of the following types of non-residential care your organisation provides?

- Day care 1
- Meals on wheels 2
- Home Help 3
- Other (specify) 4
- None of these 5
- Don't Know Y

Q9a And can I just check, how many people aged 65 and over currently use the social care services that your organisation provides?

ENTER NUMBER

Thank you very much for your co-operation, that's all the information I need for now. We'll send the information out within the next couple of weeks, explaining what you will need to do.

Annex 6 – Invitation to take part letter for users

PSSRU
University of Kent

Date

Dear Service User,

We would like to invite you to take part in a research study for the University of Kent being funded by the government. The aim of the study is to find better ways to measure the quality of social care services, such as day care services, for people aged 65 and over. The questionnaire will ask you about your views and experiences of using such services.

The University of Kent has commissioned BMRB Social Research, an independent research organisation, to carry out the survey on its behalf. We would like you to complete the questionnaire and return it to BMRB free of charge in the envelope provided. All the information you provide BMRB will be kept confidential

Enclosed with this letter is an information sheet which provides more details about the study.

If you have any questions about taking part please do not hesitate to call Alice Fitzpatrick at BMRB on 020 8433 4069 or email alice.fitzpatrick@bmrb.co.uk.

Thank you for your time and interest in this research.

Yours sincerely,

Annex 7 – Participant information sheet for participants

Participant Information Sheet
Day care services research study

You are being invited to take part in a research study by completing a questionnaire about your experiences and views on the care services that you use or have some contact with. You have also been invited to talk to a researcher about your experiences. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You can ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
The aim of the study is to explore the experiences and views of people who use or have contact with day care services. The findings from the study will be used to help to decide how to develop the services in the future.

Why have I been chosen?
You have been chosen because you are a user of one or more care services. We are very interested to find out about your views and experiences of this.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your relationship with any of the services that you use or have contact with.

What will happen to me if I take part?
If you fill out the questionnaire and return it to us on its own then that will be the end of your part in the research and we would like to thank you. If you would be willing to talk to a researcher in more detail about your experiences then you can provide us with your contact details at the end of the questionnaire. You will then be contacted by a trained researcher who can arrange to come to your home or wherever would be best for you to ask you about your experiences.

Will my taking part in this study be kept confidential?
Yes, all details will be kept confidential. Only researchers working on the study will have access to the information that is collected.

Who may I contact for further information?
If you would like more information about the research before you decide whether or not you would like to take part, please call Alice Fitzpatrick on 020 8433 4069 or email alice.fitzpatrick@bmrb.co.uk

Thank you for your interest in this research.

Annex 8 – Face to face interview schedule

QMF - Low Level Interventions

Interview with Low Level Intervention service users

Note: Don't know and refuse code will be added on to each question but will not be read out by the interviewer.

Before I begin, I would like to remind you that your name will not be used in the research and nobody will know that this information is yours. You do not have to answer questions if you do not want to and if you change your mind about taking part we can stop this interview at any time.

Section A: Services used

I am now going to ask you some questions about services that you might use or other support you might receive.

Q9. Have you used or visited any of the following services in the last three months?
READ OUT AND MULTICODE

1. Local authority arranged home care or home help
2. Privately arranged home care or home help
3. Lunch club
4. Meals on wheels
5. Dial-a-Ride or other transport service
6. District nurse, health visitor or other nurse
7. Occupational therapist, physiotherapist, speech or other therapist
8. Stayed overnight in hospital
9. Social worker or care manager

Thinking about other people who might help you or provide you with support or assistance:

Q10. Do you get any help or support from family members, neighbours, friends or other informal carers?

1. Yes: my spouse/partner helps me
2. Yes: my child(ren) help me
3. Yes: my friend / neighbour helps me
4. Yes : 'other' helps me (please specify).....
5. No: I do not get any informal help or support

IF Q10=1 OR 2 OR 3 OR 4, RECEIVE INFORMAL HELP, ASK Q11, Q12
Q11. In total how many people help you (provide informal care) per week?

ENTER NUMBER

Q12. Thinking only about the last 7 days, in total, how many hours would you say *all* people providing informal care spent helping, supporting or assisting you?
IF NECESSARY: Please only include informal care

1. 1 to 5
2. 6 - 10
3. 11 or more

We have just talked a bit about the types of services people receive; we are also interested in whether people have any aids or equipment to help them in their own homes.

Q13. Do you have any aids or equipment that help you to manage in your home?
IF NECESSARY: By this we mean things such as fall alarms, raised toilet seats, flashing door bells and anything else that helps you manage in your home

1. Yes
2. No

IF Q13 = 1. YES, ASK Q14
Q14. What aids or equipment do you have to help you manage in your home?
READ OUT AND CODE ALL THAT APPLY

1. Equipment for daily living such as raised toilet seats, teapot tippers
2. Minor adaptations costing less than £1000 for example grab rails, lever taps
3. Home Nursing Equipment such as commodes, pressure relief mattresses
4. Ancillary equipment for sensory impairments for example flashing doorbells
5. Communication aids low- and hi-tech aids for people who are speech impaired, for example communication books, digital amplifiers for people whose voices cannot be easily heard)
6. Telecare equipment such as falls alarms, gas escape alarms
7. Other (specify)

ASK ALL
Q15. Have you had any major adaptations, costing over £1000 to your home to help you manage more easily? For example, some people have stair lifts fitted to help them get up and down the stairs and other people have a walk in shower fitted to <u>replace</u> their bath.
INTERVIEWER NOTE: It doesn't matter whether or not the respondent personally paid for the adaptation.

1. Yes
2. No

IF Q15=1, YES, ASK Q16, Q17
Q16. Did you or your friends / relatives buy any of these yourselves?

1. Yes: all of them
2. Yes: some of them
3. No: none of them

IF NOT Q16 = 1
Q17. Did Social Services provide any of these for you in the last 12 months?

1. Yes
2. No

Section B: Health

I would now like to ask you some questions about your health and how you are feeling at the moment. So:

Q18. Looking at the options on this card, how would you describe your health in general?
SHOWCARD K1

1. Very good
2. Good
3. Fair
4. Bad
5. Very bad

Q19. Still thinking about your health, which of the following statements would you say best describes your own mobility?
READ OUT

1. I have no problems in walking about
2. I have some problems in walking about
3. I am confined to bed

Q20. In general, which of the following statements best describes your ability to care for yourself (washing and dressing)?
READ OUT

1. I have no problems with self-care
2. I have some problems washing or dressing myself
3. I am unable to wash or dress myself

Q21. In general, which of the following statements best describes your ability to perform activities of your choice (such as work, study, housework, family or leisure activities)?
READ OUT

1. I have no problems with performing my usual activities
2. I have some problems with performing my usual activities
3. I am unable to perform my usual activities

Q22. In general, which of the following statements best describes the amount of pain you experience?
READ OUT

1. I have no pain or discomfort
2. I have moderate pain or discomfort
3. I have extreme pain or discomfort

Q23. Which of the following statements best describes how you feel in general?
READ OUT

1. I am not anxious or depressed
2. I am moderately anxious or depressed
3. I am extremely anxious or depressed

Q24. Compared with your general health over the past 12 months, how would you describe your health state today? Would you say it is…
READ OUT

1. Better
2. Much the same
3. Worse

Q25. Thinking about your hearing, would you say that your hearing is:
READ OUT

1. Satisfactory and you don't use a hearing aid
2. Satisfactory when you use your hearing aid
3. Poor, and you don't have a hearing aid
4. Poor, even with a hearing aid

Q26. Thinking about your sight/vision, would you say that your sight is:
READ OUT

1. Perfectly good
2. Not as good as it used to be
3. Stops you reading or watching TV
4. You are registered blind

Q27. Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that you have had trouble with over a period of time, or that is likely to affect you over a period of time.

1. Yes
2. No

IF Q27=1, YES, ASK Q28
Q28. Does this illness or disability (do any of these illnesses or disabilities) limit your activities in any way?

1. Yes
2. No

ASK ALL
Q29. May I ask, have you had a stay in hospital as an inpatient, staying overnight or longer during the past 12 months
INTERVIEWER: if having trouble remembering, prompt by saying 'Since (1st of Month one year ago)'

1. Yes
2. No
3. Don't know

If Q29 = YES
Q30. How many times have you stayed in hospital as an inpatient?
IF NECESSARY: In the last 12 months

WRITE IN

If Q29 = YES
Q31 Were any stays for 1 week or more?

1. Yes
2. No
3. Don't know

If Q31 = YES (If q30 = 1 then force Q31 to = 1)
Q32 How many?

WRITE IN

I am now going to run through some more activities and ask you to tell me how easy it is for you to perform each one in terms of the statements on this card.

Q33. Do you usually manage to…..
SHOWCARD K2

a. Get dressed or undressed
b. Get in and out of bed or a chair
c. Wash your face and hands
d. Prepare hot meals
e. Walk at least 10 minutes

1. On your own without help
2. On your own with difficulty
3. Not at all on your own

Q34. Do you use a wheelchair?

1. Yes
2. No

Q34a. Do you use a mobility scooter?

1. Yes
2. No

Q35. Do you deal with finances and paperwork - for example, paying bills, writing letters - by yourself?

1. Yes
2. No

IF Q35=2, NO, ASK Q35a, Q35b
Q35a. Could you if you had to?

1. Yes
2. No

Q35b. Does someone do this for you?

1. Yes
2. No

Next, I would like to ask you about your wellbeing and quality of life. There will be a list of statements. Some of the statements may seem slightly odd to you, but they are part of a list of statements that different people have used to describe their lives and how they feel.

Q36. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole? Would you say it is……READ OUT

1. So good, it could not be better
2. Very good
3. Good
3. Alright
4. Bad

5. Very bad
6. So bad, it could not be worse
7. Don't know

Section C: Impact of services (CfB)

It's quite difficult to fully measure the impact of services and support. We think people themselves are best able to judge what things would be like if they didn't have services or support. The next set of questions may seem strange to you but we are trying to get your views on the impact of the support you receive.

Q37. Thinking about your home, which of the following statements best describes your present situation?
READ OUT

1. My home is as clean and comfortable as I want
2. My home is less clean and comfortable than I want
3. My home is not at all as clean or comfortable as I want

Q38. Do the day care services that you use help you to keep your home clean and comfortable?

1. Yes
2. No
3. Don't know

ASK ALL
Q39. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation?
READ OUT

1. My home would be as clean and comfortable as I want
2. My home would be less clean and comfortable than I want
3. My home would be not at all as clean or comfortable as I want

ASK ALL
Q40. Which of the following statements best describes how safe you feel? Not feeling safe could be due to fear of abuse, falling or other accidental physical harm, and fear of being attacked or robbed.
READ OUT

1. I feel as safe as I want
2. Sometimes I do not feel as safe as I want
3. I never feel as safe as I want

Q41. Do the day care services that you use help you to feel safe?

1. Yes
2. No
3. Don't know

Q42. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation?
READ OUT

1. I would feel as safe as I want
2. Sometimes I would not feel as safe as I want
3. I would never feel as safe as I want

Q43. Thinking about the meals you eat, which of the following statements best describes your present situation?
READ OUT
IF NECESSARY: By right meals we mean food that is sufficient, healthy and nutritious, and suitable for any dietary requirements that you may have.

1. I eat the meals I like when I want
2. I don't always eat the right meals I want, but I don't think there is a risk to my health
3. I don't always eat the right meals I want, and I think there is a risk to my health

Q44. Do the day care services that you use help you to eat enough food that is suitable for you?

1. Yes
2. No
3. Don't know

Q45. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation?
READ OUT
IF NECESSARY: By right meals we mean food that is sufficient, healthy and nutritious, and suitable for any dietary requirements that you may have.

1. I would eat the meals I like when I want
2. I would not always eat the right meals I want, but I don't think there would be a risk to my health
3. I would not always eat the right meals I want, and I think there would be a risk to my health

Q46. Thinking about the way you look and feel, which of the following statements best describes your present situation?
READ OUT

1. I feel clean and wear what I want
2. I sometimes feel less clean than I want or sometimes can't wear what I want
3. I feel much less clean than I want, with poor personal hygiene

Q47. Do the day care services that you use help you to feel clean and wear what you want?

1. Yes
2. No
3. Don't know

Q48. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation?
READ OUT

1. I would feel clean and wear what I want
2. I would sometimes feel less clean than I want or sometimes couldn't wear what I want
3. I would feel much less clean than I want, with poor personal hygiene

Q49. Thinking about your usual activities including leisure, doing things for others and paid or unpaid employment, which of the following best describes your present situation?
READ OUT

1. I do the activities I want to do
2. I do some of the activities I want to do
3. I don't do any of the activities I want to do

Q50. Do the day care services that you use help you to do the activities you want to do?

1. Yes
2. No
3. Don't know

Q51. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation? READ OUT

1. I would do the activities I want to do
2. I would do some of the activities I want to do
3. I wouldn't do any of the activities I want to do

Q52. Many people value being in control of their daily lives and having independence. By 'control over daily life' we mean you are the one making decisions about your life, and having the choice to do what you want, when you want. Which of these statements best describes your present situation? READ OUT

1. I have as much control over my daily life as I want
2. Sometimes I don't feel I have as much control over my daily life as I want
3. I have no control over my daily life

Q53. Do the day care services that you use help you to have control over your daily life?

1. Yes
2. No
3. Don't know

Q54. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation? READ OUT

1. I would have as much control over my daily life as I want
2. I sometimes wouldn't have as much control over my daily life as I want
3. I would have no control over my daily life

Q55. Which of the following statements best describes your social situation?

By social situation we mean keeping in touch with people and spending time with people that you want to be with.
READ OUT

1. My social situation and relationships are as good as I want
2. Sometimes I feel my social situation and relationships are not as good as I want
3. I feel socially isolated and often feel lonely

Q56. Do the day care services that you use help you to keep your social situation as good as you want?

1. Yes
2. No
3. Don't know

Q57. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation? READ OUT

1. My social situation and relationships would be as good as I want
2. Sometimes my social situation and relationships would not be as good as I want
3. I would feel socially isolated and often feel lonely

Q58. Which of these statements best describes how worried or concerned you feel? READ OUT

1. I feel free from worry and concerns on a day-to-day basis
2. I sometimes feel worried and concerned
3. I feel very worried and concerned on a daily basis

Q59. Do the day care services that you use help you to feel less worried or concerned about your daily life?

1. Yes
2. No
3. Don't know

Q60. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation? READ OUT

1. I would feel free from worry and concerns on a day-to-day basis
2. Sometimes I would feel worried and concerned
3. I would feel very worried and concerned on a daily basis

Q61. Which of the following best describes your present situation?
READ OUT

1. I am treated by other people with the dignity and respect that I want
2. Sometimes I am not treated by other people with the dignity and respect that I want
3. I am never treated with the dignity and respect that I want

Q62. Do the day care services that you use contribute to you feeling that you are treated with dignity and respect?

1. Yes
2. No
3. Don't know

Q63. If you didn't get the help that you do from the day care services you use, and other help did not step in, which of the following statements do you think would best describe your situation? READ OUT

1. I would be treated by other people with the dignity and respect that I want
2. Sometimes I would not be treated by other people with the dignity and respect that I want
3. I would never be treated with the dignity and respect that I want

Section D: Quality of care / support

The next section is about your views on the help, care and support that you receive from the day care services that you access. I would like you to think specifically about the *quality* of the services that you receive now, that is, how well they do what they are supposed to do.

Q64. Overall, how satisfied are you with the support you get from day care services? Would you say you were….
READ OUT

1. Very satisfied
2. Quite satisfied
3. Neither satisfied nor dissatisfied
4. Quite dissatisfied
5. Very dissatisfied

Q65. Please could you tell me whether you agree or disagree with the following statement?
It was easy to find out about day care services that might be able to help me

IF AGREE OR DISAGREE: Is that strongly or slightly agree/disagree?

1. Strongly agree
2. Slightly agree
3. Slightly disagree
4. Strongly disagree

Q66. Would you say that the people who help support or assist you at the day care centre
READ OUT

1. Always do the things you want done
2. Nearly always do the things you want done
3. Sometimes do the things you want done
4. Never do the things you want done
5. Does not apply to me

Q67. And overall, how do you feel about the way you are treated by the people who help support or assist you at the day care centre? Such as whether they are understanding and treat you with dignity and respect? Would you say you…

READ OUT

1. Are always happy with the way that the care workers treat you
2. You are usually happy with the way that the care workers treat you
3. You are sometimes happy with the way that the care workers treat you
4. or you are never happy with the way that the care workers treat you?

Q68. Would you describe your relationship with the people who help support or assist you at the day care centre
READ OUT?

1. Excellent
2. Good
3. Okay
4. Bad
5. Does not apply to me

Q69. How often do you visit the day care centre?

1. Once a week
2. Twice a week
3. Three times a week
4. More than three times a week

Q69a. Do you visit the day care centre as much as you want?

1. Yes, I visit as much as I want
2. No, I would like to visit more than I do
3. No, I visit more than I want

Q70. Do you think the people who help support or assist you at the day care centre are professional and do a good job…
READ OUT

1. Always
2. Usually
3. Sometimes
4. Never
5. Does not apply to me

Q71 In terms of contact with other people, which one best describes your current social situation?

1. I have daily contact with one or more people that I am fond of (face-to-face, by phone etc.)
2. I have weekly contact with one or more people that I am fond of (face-to-face , by phone etc.)
3. I have *less than* weekly contact with at least one person that I am fond of
4. I never or almost never have contact with people that I am fond of

[IF Q71 = 1, 2 or 3] ask 71a
Q71a Who are the people that you have contact with?

1. Your husband, wife or live-in partner
2. Other family members
3. Friends
4. Others, specify [.....]

[IF Q71 = 2,3,4 ask Q72]
Q72. Do you usually have days when you don't have contact with anyone, including people that you don't know personally?

1. Yes
2. No

Section E: Background Information

I would now like to ask you for a few further details about yourself

Q2. Who do you live with?
CODE ALL THAT APPLY
1. I live alone
2. With spouse/partner
3. With parents
4. Others (including children and other relatives)

IF Q2=4
Q2a. How many?
WRITE IN
Q2b. Do you have any pets

1. Yes
2. No

Q3. To which of these groups do you consider you belong to?
Show Card and ask:
SHOWCARD K3

White:
A. White – British
B. White – Irish
C. White – Other White background
Mixed:
D. Mixed - White and Black Caribbean
E. Mixed - White and Black African
F. Mixed - White and Asian
G. Mixed - Any other Mixed background
Asian or Asian British:
H. Asian or Asian British - Indian
I. Asian or Asian British - Pakistani
J. Asian or Asian British - Bangladeshi
K. Asian or Asian British - Other Asian background
Black or Black British:
L. Black or Black British - Caribbean
M. Black or Black British - African
N. Black or Black British - Other Black background
Chinese or other ethnic group:
O. Chinese
P. Any other

Q4. What is your current housing status?

1. Owner occupier / mortgage

2. Private rented
3. Provided by local authority / housing association
4. Live here rent free (inc. rent free in relatives homes)
5. Other (please state)

ASK IF Q4 = 1
Q4a. and how many bedrooms do you have?

WRITE IN

Q6a. Do you have a garden?
ONLY INCLUDE PRIVATE GARDENS AND NOT COMMUNAL AND NOT ALLOTMENT

1. Yes
2. No

Q6b. Do you live in sheltered housing?
INTERVIEWER NOTE: a property with an emergency alarm system and access to a warden.

1. Yes
2. No
3. Not sure

Q6c. Do you live in extra care housing?
INTERVIEWER NOTE: a property (usually clustered with others that are similar) with an emergency alarm system and an on site care team of nurses/care workers to help with daily care needs.

1. Yes
2. No
3. Not sure

Q6. Are you involved in any unpaid voluntary work?

1. Yes
2. No

If Q6=1, yes involved in Voluntary work
Q8a.How many hours per week, do you spend doing this on average?

ENTER NUMBER

Q7. Do you receive any of these benefits?
READ FROM THE LIST AND RECORD RESPONDENTS ANSWER TO EACH.

a. Pension credit (Minimum Income Guarantee)
b. Working/child tax credit
c. Attendance Allowance
d. Disability Living Allowance - Mobility
e. Disability Living Allowance - Care
f. Incapacity benefit
g. Housing benefit
h. Income support
i. Severe disablement allowance

1. Yes

2. No
3. Don't know

Q8. Do you mind if I ask you what your total income is, from all sources, including benefits and credit, per week (after tax)?
INTERVIEWER: If couple, obtain joint income.

1. A
2. B
3. C
4. D
5. E
6. F
7. G
8. H
9. I
10. J
11. K
12. L
13. SPONTANEOUS: Nothing/No work or scheme

Don't know
Refused

The list on the showcard is as follows:

	Annual	Weekly	Monthly
1.K	Under £2,500	Under £50	Under £200
2.J	£2,500 - £4,999	£50 - £99	£200 - £399
3.D	£5,000 - £9,999	£100 - £199	£400 - £829
4.F	£10,000 up to £14,999	£200 - £289	£830 - £1,249
5.C	£15,000 up to £19,999	£290 - £389	£1,250 - £1,649
6.H	£20,000 up to £24,999	£390 - £489	£1,650 - £2,099
7.L	£25,000 up to £29,999	£490 - £579	£2,100 - £2,499
8.A	£30,000 up to £34,999	£580 - £679	£2,500 - £2,899
9.I	£35,000 up to £39,999	£680 - £769	£2,900 - £3,349
10.B	£40,000 up to £44,999	£770 - £869	£3,350 - £3,749
11.E	£45,000 up to £49,999	£870 - £969	£3,750 - £4,149
12.G	£50,000 or more	£970 or more	£4,150 or more

Q71. How easy or difficult was it to fill in the paper questionnaire you completed before taking part in this interview?
IF NECESSARY: was that very or fairly easy/difficult?

1. It was very easy
2. It was quite easy
3. It was neither difficult or easy
4. It was quite difficult
5. It was very difficult

Q1b. INTERVIEWER: RECORD WHO WAS PRESENT DURING THE INTERVIEW
CODE ALL THAT APPLY

1. No-one else in room
2. Carer
3. Relative
4. Neighbour

5. Spouse/ Partner
6. Other (specify)

Q1c. INTERVIEWER CODE WHETHER THE INTERVIEW WAS GIVEN

1. With the service user alone
2. With the assistance of someone else

Q1d. INTERVIEWER CODE RELATIONSHIP TO RESPONDENT? (e.g. carer, relative)

1. Carer
2. Relative
3. Neighbour
4. Spouse/ Partner
5. Other (specify)

Thank you for taking part in this interview. Your opinions and experiences are very important to us. All the data we collect and analyse are stored and treated in an anonymous way and no names are attached to the results.

Annex 9 – Theories of Need, Well-being, and Quality of Life

Utilitarianism

Subjective well-being is an important aspect of quality of life or well-being in general. Indeed, one of its main components – happiness – is the foundation of the school of thought of utilitarianism which was initially propounded in the nineteenth century by Jeremy Bentham and James Mill, then developed by John Stuart Mill (West, 2006). Utilitarianism provides a vision of the goal of the ideal society: one where utility is maximised. Utility in its most basic form is defined as the mental state of pleasure or happiness and its opposite, disutility, is pain or suffering. Thus a utilitarian society is one which strives to achieve the greatest happiness of the greatest number of its citizens. Two aspects of utilitarianism are central to discussions of quality of life. The first is at a theoretical level and is related to notions of values and desires. The second is at a practical level and relates to measuring utility in the material world.

Its theoretical approach has the merit of being easy to understand and intuitively unproblematic. For example, other things being equal, it is clearly better for each individual to be more, rather than less happy, and similarly, better for a society to have a greater rather than a smaller number of happy people. The centrality given by utilitarianism to the self-assessment by each person of their own well-being – to their own happiness – places great emphasis on the integrity, dignity and liberty of people as autonomous individuals (West, 2006). This is an important moral stance of utilitarianism.

In its practical manifestation, utility is perhaps the most straightforward of all quality of life constructs to grasp: essentially we do what makes us happy. In relation to the material world of goods and services the formula for achieving utility can be expressed as: happiness = getting what you want = choosing to purchase and consume certain goods and services (Phillips, 2006). In other words, our happiness can be measured by our purchases. The huge advantage that utilitarianism has over most quality of life constructs is that these purchases are easily measurable – in money. Even more importantly, from a utilitarian perspective it can be seen that utility increases along with opportunity to consume i.e. high levels of income lead to high levels of utility. Thus, income can be used as a measure or indicator of utility, at least for all aspects of the material world that have a price on them. By this rationale, wealthy people have more utility than poor people and it is the countries with the highest levels of GNP that have the most utility.

The simplicity of utilitarianism makes it an extremely attractive approach to the study of quality of life and well-being, however, there are some conceptual and theoretical problems associated with equating quality of life with happiness. There is considerable debate about whether happiness can always be equated with quality of life. For this to be the case, our best interests must always be met by doing the things that make us happy, or in other words, by fulfilling our desires rather than by doing things which can be seen as meaningful, valuable or worthwhile (Phillips, 2006). Similarly, in this happiness based utilitarian world it will always be „better" to do things that are not worthwhile but which do make us happy, than to do things that are worthwhile but do not make us happy. To take a trivial example, in this simplistic version of the utilitarian world it will always be better (or will maximise utility) to eat sweets than to brush one"s teeth. It is clear therefore that there is an intrinsic tension in the utilitarian positions. On the one hand, respect for the integrity and freedom of choice of the

individual is paramount, along with a corresponding distrust of paternalism and interference in the lives of individuals. On the other hand, the inherent subjectivity of the approach, centred as it is on the individual"s happiness, sets criteria for quality of life that can be met at a very low level of accomplishment or achievement or indeed of any objective assessment of what is a high quality existence for a human being (Phillips, 2006). This final criticism is perhaps one of the most difficult for utilitarianism. Phillips (2006, p. 64) uses the example of the „happy slave" to illustrate this. In this scenario, it makes sense for a slave – or a woman in a society that restricts women"s rights – to adapt to their situation and make the best of it rather than to rail against an inevitable servitude. Indeed, a very well adapted slave or disempowered woman might even be happier than someone in an objectively better situation in the same society, so would thus be assigned a higher level of utility. This might be considered inappropriate in any measure of comparative well-being which purports to give a rounded perspective on quality of life.

Another criticism levelled at utilitarianism is whether or not we can actually infer utility from purchase and consumption. Kahneman, Wakker and Sarin (1997) question whether observed choices of purchase of goods and services, or decision utility, actually do represent real utility. In order for this to be the case, then this decision utility must always result in experienced utility, which in basic utilitarian terms is what utilitarianism is all about – pleasurable mental states. According to Kahneman et al. (1997) experienced utility is governed by a distinctive normative logic, is measurable, and is empirically distinct from decision utility. More importantly from a quality of life perspective, they claim that there are important empirical differences between experienced utility and decision utility which raise doubts as to whether we can in fact infer utility from consumption. They claim that in general, people are not effectively able to maximise their experienced utility because of their limited understanding and ability to predict their own enjoyment of goods and activities. (Stewart, 1996) also suggests that people"s actual consumption choices are constrained and mediated by inter-personal expectations and social norms as much by utility and logic or rationality. Thus purchases, and therefore income are less clearly connected with utility, with happiness, with pleasure and with quality of life. Kahneman et al. (1997) argue therefore, that an increase in purchases or an increase in income does not necessarily mean an increase in quality of life.

On the basis of some of the evidence above, Griffin (1986, p. 10) concludes that „the objection to the actual-desire account is overwhelming" and (similar to the example given by Phillips) cites the example of undiagnosed diabetics whose revealed preference, actual desire and – according to utilitarianism – experienced utility is to consume sugar when their best interests are to take insulin instead. His response is to develop a theory of well-being based not on actual desires but on informed desires or rational choices – prudential values.

Prudential values

One of the most important representations of informed desires is that of prudential values, initiated by James Griffin (Griffin, 1986, 1996) and developed by Mozaffar Qizilbash (Qizilbash, 1997, 1998). Prudential values are values which make any human life „go better" and are predicated on a notion of „the good life" based on our essential humanity. The prudential values approach is not based on people"s actual desires but on what their desires would be if people were fully informed. This, Griffin claims, overcomes the „happy slave" problem, because informed desires appeal „to what really increase or decrease the quality of

their lives. It does not matter if some people have modest expectations: their informed desires include what they would want if they raised their sights" (Griffin, 1986, p. 47). Similarly an informed desire can be the exact opposite of an actual desire if a person desires what is bad for them, because informed desires relate to *real* rather than *believed* benefit.

The prudential values approach begs one critical question: what exactly would people desire if they were fully informed? Actual desires, in principle at least, can be ascertained by asking people and/or observing their behaviour, but informed desires are not so easily accessible. Indeed, in one sense, they are not empirically accessible at all because fully informed desires are a utopian goal - increases in knowledge and understanding ensure that becoming fully informed is a dynamic and ever changing objective.

In terms of identifying the criteria for appropriate informed desires, Griffin (1986) starts from the position that it is appropriate for people to behave prudently and thus he proposes an approach based on prudential values. Prudential values concern what makes a person"s life valuable to themselves. Griffin (1986, p. 119) summarises prudential values thus: „Basic prudential values provide us with an important standard for judging many (ordinary) human lives. They let us say, though only roughly, how good the life is, how it could be better, and how it compares to other lives."

Griffin (1986, p. 19) states that the prudential values approach „has to do with everything that makes a life good simply for the person living it", rather than being concerned with moral values which are based more generally on abstract principles of what is right or wrong. He sees a thing which is prudentially valuable „as enhancing life in a general intelligible way, in a way that pertains to human life, not one particular person"s life" and „anything is prudentially valuable if it is generally intelligible as valuable and as valuable for any (normal) human" (Griffin, 1986, p. 27).

More simply, Qizilbash (1997, p. 262) identifies prudential values as values which „make any human life better." Qizilbash and Griffin both make links between actual desires, informed desires, values and interests, but also accept that in many circumstances desires may not relate to genuine prudential values: „A more direct way to approaching prudential values may be to look at the nature of a characteristically human life, and the grounds of our mutual intelligibility as human beings" (Qizilbash, 1997, p. 263). This is an important conceptual point of departure in that a new criterion for quality of life has been introduced that is completely distinct from desires, whether actual or informed – an appeal to the notion of what it is that makes us distinctively members of humanity. In essence, according to this perspective, it is the nature of our humanity which provides the context and framework for assessing the criterion of desires being informed rather than a criterion of „value free" scientific knowledge as the basis for being informed.

The notion of being characteristically human also moves away from an individual-centred to a more inter-subjective approach that links to a necessity of shared human values. These shared values necessary for mutual intelligibility and for seeing each other as humans are identified as core prudential values and are values which will make any human life go well. Core values are seen as essential to the definition of humanity: „To see each other as humans is to see each other as people whose lives fare better with the elements of core value" (Qizilbash, 1998, p. 64). Qizilbash identifies other prudential values as being non-core. These are values which give human life meaning, which enhance life in a general way,

but which are not necessary for mutual intelligibility. An important non-core prudential value would be accomplishment. A life of accomplishment would, other things being equal, be better and more prudentially valuable than a life without accomplishment, but accomplishment is not a requirement of mutual intelligibility and so therefore, although important, is not seen as core.

Both Griffin and Qizilbash provide lists of prudential values. However the prudential values lists have a different status to others in that they are seen as indicative rather than definitive. Griffin accepts that the list he provides is culturally defined and is open to amendment but he makes the point that prudential deliberation would lead everyone to a list of some kind, and that our shared human values would – or should – lead to all the lists having considerable similarities. The following list is based on Griffin (1986; Griffin, 1996).

(a) Accomplishment
(b) Components of a characteristically human existence:
    Agency
    Autonomy
    Liberty
    Basic capabilities that enable one to act:
        limbs that work
        minimum material goods that keep body and soul together
        freedom from great pain and anxiety
(c) Understanding, including:
        self-knowledge
        knowledge about the world
        being in touch with reality
        freedom from muddle, ignorance and mistake
(d) Enjoyment, including general pleasures, the day-to-day textures of life and appreciating beauty
(e) Deep personal relations: deep, authentic, reciprocal relations of friendship and love…they in themselves go a long way towards filling and completing life.

A number of issues have been raised in relation to the list provided by Griffin. For example, „limbs and senses that work" are certainly attributes that would make any human life go better but it is not clear in what sense they are values, and even less so desires. Phillips (2006) suggests that these could at best be called prudential *attributes*, and these attributes can then be seen as facilitating the prudential value of autonomy because impairment can diminish autonomy. „Basic capabilities that enable one to act" similarly do not fit comfortably as values, even though there are good pragmatic grounds for including capabilities among those things that make a human life go better. Capabilities, epitomised in the work Amatrya Sen (1993), are generally seen to be a different kind of characteristic than values, and therefore the inclusion of a capability set within a set of values may indicate a lack of precision and clarity.

Qizilbash (1998) raises a question too over the status of „the minimum material goods that keep body and soul together" in that these material goods are instrumental rather than intrinsic in their nature. He recommends being more specific about what actually constitutes the intrinsic goal of keeping body and soul together and thus includes: minimum levels of

nutrition, health, sanitation, shelter, rest, security, basic physical and mental capacities, and literacy.

Qizilbash also contends that the list is incomplete because it does not include self-respect, dignity or aspiration – although the last of these is perhaps implicit in Griffin"s category of accomplishment. The case Qizilbash (1998, p. 66) makes for self-esteem is important in relation to a holistic notion of quality of life:

> *Without some notion of our own importance we would not aim to make something of our lives…Dignity is closely related to agency…self-respect may have its basis in complex social relationships. If I count as nothing, or close to nothing, in the society I live in, my self-esteem may be so poor that I cease to care about my own life or destiny, let alone pursue accomplishments or significant relations.*

The list of prudential values provided by Qizilbash (1998, p. 67) is perhaps more clear, consistent and comprehensive than that given by Griffin and is as follows:

1. minimum levels of nutrition, health, sanitation, shelter, rest and security;
2. certain basic intellectual and physical capacities and literacy;
3. certain levels of self-respect and aspiration;
4. enjoyment;
5. autonomy or self-determination;
6. liberty;
7. understanding;
8. significant relations with others and some participation in social life;
9. accomplishment.

By substituting informed desires for actual desires the way is opened for a transformation from the essentially one-dimensional, individualistic and atomistic utilitarian approach to an essentially multidimensional, social and inter-subjective prudential values approach to conceptualising and measuring quality of life. A utilitarian approach is – at least in relation to material desires – empirically straightforward in that utility is measured in money values which can be added together to give a total. The utilitarian approach may well be somewhat flawed but it has the advantage of being clear-cut and intuitively easy to grasp. The prudential values approach is far more complex in its multiple plurality, but this is inevitable given that the reality it aims to represent is in itself plural and complex.

In addressing the desires that people would have if they were fully knowledgeable, rather than what people actually desire, and in addressing prudence rather than hedonism, prudential values tap into a deeper and more aspirational vision of human nature than that of utilitarianism. However, any move to replace what people actually choose to desire will reduce their independence and in at least one sense, their autonomy. It also introduces the possibility of paternalism, of being told that what is best for you may not be what you want to do (Phillips, 2006). Griffin perhaps wants everything his own way because he accepts that autonomy is reduced by moving away from actual desires and yet it is an important facet of any enlightened person"s conception of „the good life." He maintains, however, that autonomy is not a be-all or end-all and cannot be judged in isolation. In other words, although it is important, it should not be privileged over other important values. This is a

central issue in operationalising non-utilitarian approaches to quality of life which is addressed by Sen (1993).

The fundamental question about a prudential values approach relates to the security of its foundations: it is based on the two concepts of informed desires and a shared realm of human values necessary for intelligibility. Both of these are at a rather abstract level and lead to a centrality of core values associated with mental state and understanding rather than of survival, subsistence and physical thriving. These latter, more visceral, attributes are more closely related to a quality of life tradition based on addressing needs rather than to values.

Needs

The notion of need is refreshingly simple and straightforward compared to that of informed desire and prudential values. A need is a necessity and, in the context of quality of life, meeting needs provides the necessities for survival or, slightly more ambitiously, for a minimally decent life. At its most basic level, a needs based approach deals with food, shelter and elementary health care and education services.

Unlike the prudential values approach, which deals with abstract values, the basic needs approach deals with practicalities. It differs fundamentally from utilitarianism both conceptually, in distinguishing between desires and needs, and in terms of measurement. Utility, or at least decision utility, is measured in terms of money; and a nation"s utility is measured in terms of its national income. From a basic needs perspective however, the absolute requirement for quality of life is not related to income, and average or per capita income in a nation is seen as an irrelevance, given that many people might not have their basic needs met even in a society with high average income if that society is highly unequal.

The basic needs approach is modest in scope, but it does provide an absolutely firm foundation for a decently acceptable life where neither prudential values or utilitarianism do (Wiggins, 1998). The basic tenets of the basic needs approach are that everyone should be entitled to expect, at the very least, a minimally decent life and have access to food, water, shelter, and medical services and education (Phillips, 2006). The basic needs approach has nothing to say about quality of life above that level. The most minimalist basic needs approach (known as basic goods) is comprised of nutrition, basic health services and some degree of educational attainment (Stewart, 1996). The underlying rationale behind a basic goods approach is that these three items are probably universal and uncontroversial elementary human needs. They are also relatively easy to identify and there are widely available sets of international indicators on life expectancy, malnutrition among children and on educational attainment that can be used as proxy measures. However, according to Phillips (2006) there is a problem. In amalgamating the three aspects of basic goods, should they be equally weighted? Or, for example, is life expectancy up to a certain age more important than literacy and, if so, then how is that age decided?

Public goods are the key to a basic needs strategy in that the provision, or at least the very guaranteeing, of basic health and educational services for all has to be the responsibility of the state (Stewart, 1996). This focus on public goods has also been the source of criticism levied at the approach i.e. a focus on goods and services rather than the quality of human lives (Sen, 1982). Alkire (2002b) also points out the dangers of coercion where the meeting

of basic needs is imposed upon an unwilling population, for example, through enforced (culturally inappropriate) immunisation.

Although it may be true that a basic needs approach tends to neglect differences in personal characteristics (such as impairment) and focuses very strongly on the public provision of goods, its strengths lie in its simplicity and clarity with regard to its objectives. These are summarised effectively by Stewart (1996, p. 64):

> *The basic needs approach is based on a simple moral imperative – that everyone should have access to minimally decent condition of life and that this objective should be given priority over other objectives. It thus represents a quite robust political philosophy for poor societies, which had implications for income distribution and desirable patterns of consumption and suggests strong policy conclusions … In practice, something very close to a basic needs approach has to be adopted to yield policy conclusions in poor countries.*

This is not only important for poor countries, it also has profound implications for many developed countries – those with high levels of inequality and a significant proportion of their population living below the basic needs threshold (Wilkinson, 1996).

The basic needs approach is appealing, particularly due to its incontrovertible moral imperative of ensuring the right to a basic minimum level of survival for all people. However, it is perhaps not applicable to the wider world. While there is a strong case for using basic needs as the primary quality of life measure in countries with very high levels of deprivation, it becomes rather a blunt instrument for the less deprived developing nations and becomes almost totally undiscriminating among more egalitarian, wealthier countries. Here, there is a case for introducing other aspects of quality of life as being more *important* than a small marginal addition to an already long life expectancy or high level of educational attainment (Qizilbash, 1998).

The Human Development Index (HDI)

Rather than being based on „what makes any human life go well" or being „characteristically human" as is the case with the prudential values approach, the human development approach is centred on *well-being* (UNDP, 1990). Human development was initiated by the United Nations Development Programme (UNDP) and, like basic needs, is aimed primarily at developing countries. The central idea of the human development approach is that well-being is central to the goal of development and that human beings form the major development resource:

> *People are the real wealth of a nation. The basic objective of the development is to create an enabling environment for people to live long, healthy, and creative lives…human development is a process of enlarging people's choices. The most critical ones are to lead a long and healthy life, to be educated and to enjoy a decent standard of living. Additional choices include political freedom, guaranteed human rights and self-respect.* (UNDP, 1990, pp. 9-10).

In its initial formulation the HDI had three indicators: (1) life expectancy for the society as a whole; (2) literacy; and (3) the log of per capita GNP, adjusted for international differences in

purchasing power. It has since been adjusted to take average years of schooling into account.

Conceptually, the human development approach can be placed between utility and basic needs. It draws on both of their empirical strengths but „in doing so has a resulting hybrid and weak theoretical justification" (Stewart, 1996, p. 59). Therefore, HDI is not an accurate indicator of either decision utility or the basic needs of societies. The literacy, years of schooling and life expectancy components are, in principle, non-problematic but the income variable is a societal average and therefore not sensitive to income distribution. It therefore does not effectively measure people's ability to achieve their basic needs. It has also been criticised for being „too economically dominated and not taking any account of social structures or institutions" (Gasper, 2002, p. 445).

Doyal and Gough's Theory of Human Need (THN)

Doyal and Gough's (1991) „Theory of Human Need" (THN) is something of a logical progression to a higher level of needs fulfilment. Their approach has two particular merits. The first is ideological in that Doyal and Gough insist that there is a strong moral link between the existence of needs and an obligation by societies to meet them. These needs, according to Doyal and Gough then necessarily entail corresponding social rights:

> *If human needs are the universal precondition for participation in social life, we contend that all people have a strong right to need satisfaction. This follows because membership of all social groups entail corresponding duties, yet without adequate levels of need satisfaction a person will be unable to act in accordance with these duties. It is contradictory to ask of someone that they fulfil their social duties, yet to deny them the prerequisite need satisfaction which will enable them to do so. This is why the social rights of citizenship follow from an unambiguous concept of human need.* (Gough, 1998)

The THN's second merit is theoretical in that it creates a framework firmly grounded in objective needs. The THN's theoretical starting point is the notion of universal needs which are in everyone's interest to achieve. Doyal and Gough claim that everyone has an objective interest in avoiding serious harm (which would prevent them from pursuing their vision of the good life) which in turn entails an ability to participate socially (Gough, 1998). According to Doyal and Gough, there are two universal needs based goals: avoiding serious harm; and an ability to participate. The THN structure has two levels of needs – basic (or primary) needs and intermediate needs. The THN is seen as providing external and independent standards which can be used to compare across different societies with a range of social, political and economic systems, with the ultimate goal of enabling objective human welfare to be assessed independently of cultural values (Doyal & Gough, 1991).

There are two primary needs which require to be met at what Doyal and Gough call an „optimum level": physical health; and autonomy of agency. Optimum levels of physical health can be seen as congruent with the WHO definition of health as a state of complete physical, mental and social well-being, including autonomy (WHOQOL Group, 1995, p. 1404). However, perhaps of more importance here for Doyal and Gough is survival with associated complexities relating to reduction in functional ability associated with ageing or with optimum

life expectancy. These are complex and difficult issues which have repercussions in terms of the trade-off in resources required to meet different primary and intermediate needs.

Autonomy of agency is seen by Doyal and Gough as the defining characteristic of human beings. It is defined as „the capacity to make informed choices about what should be done and how to go about doing it" (Doyal & Gough, 1991, p. 63). This insistence on *informed* choices is consistent with prudential values. According to Doyal and Gough (1991, p. 63) „autonomy requires self-confidence and is impaired when there is a deficit in three attributes: mental health; cognitive skills; and opportunities to engage in social participation." The identification of constraints on autonomy are important and is also linked with Wilkinson's (1996) proposition of the central role of self-esteem in the maintenance of health and its relationship with societal inequality.

In order to satisfy primary needs, Doyal and Gough identify eleven intermediate needs which require meeting at a „minopt" level, which is the „minimum quantity of any given intermediate need-satisfaction required to produce the optimum level of basic need satisfaction" (Gough, 2003, p. 18). These intermediate needs are as follows (Gough, 2003, p. 11):

1. Nutritional food and clean water
2. Protective housing
3. Non-hazardous work environment
4. Non-hazardous physical environment
5. Safe birth control and child bearing
6. Appropriate health care
7. secure childhood
8. Significant primary relationships
9. Physical security
10. Economic security
11. Appropriate education

Their rule for inclusion as an intermediate need is as follows: „The only criterion for inclusion in this list is whether or not any set of satisfier characteristics universally and positively contributes to physical health and autonomy. If it does then it is classified as an intermediate need" (Gough, 2003, p. 11). The first six intermediate needs contribute to physical health and the last five to autonomy.

One major difference exists between the prudential values list and the THN list – the absence of enjoyment or any related construct from the latter. Utilitarianism shares a fundamental „absence of pain" value with both prudential values and the THN and a fundamental enjoyment/pleasure value with prudential values. Thus, Doyal and Gough share with utilitarians and proponents of prudential values a strong belief in the importance of avoidance of pain as a universal goal but not in the importance of pleasure or enjoyment. Gough characterises THN as a „thin", two-stage, neo-Kantian theory: „When focussing on health and autonomy of agency it is explicitly designed to fit all human societies. It deliberately seeks, so to speak, the lowest common denominator of universalisable preconditions for human action and social participation" (Gough, 2003, p. 16).

Perhaps the most important potential criticism of THN is regarding its purported initial paternalism (Phillips, 2006). In this context, Gough accepts that the theory is embedded in people's *functionings* as outlined by the theory's authors rather than people's own choices

among their *capabilities* for functioning. Gough accepts capabilities as being the appropriate currency for the THN, thus permitting „universal goals to be identified yet individuals" rights not to pursue them to be given due weight…The functioning-capability distinction would help us to diminish the lingering charges of paternalism" (Gough, 2003, p. 16).

Sen's Approach – Capabilities

Amatrya Sen first used the term „capability" in 1979 to refer to an approach to well-being in terms of *freedoms*, particularly freedom to choose among various alternatives including: „being happy; achieving self-respect; taking part in the life of the community" (Sen, 1993). Capabilities are about a person"s ability to do valuable acts or to reach valuable states of well-being – or „doing" and „being" – together referred to as *functionings*. Thus, capabilities are to do with the freedom to pursue valuable „doings" and „beings" in order to flourish as a human being. Central to this approach is the notion of a *capability set* which refers to the alternative combinations of things a person is able to do or be. Initially, a capabilities approach seems far removed from the concept of basic needs due to its expansive and generous conception of what is valuable in human life. However, one facet of the capabilities approach, that of *basic capabilities*, covers similar ground to that covered by basic needs, and this is the aspect of capabilities that Sen has devoted much of his attention. Basic capabilities refer to the „ability to satisfy certain crucially important functionings up to certain minimally adequate levels" (Sen, 1993, p. 40). These include „escaping morbidity and mortality, being adequately nourished, having mobility etc." (Sen, 1993, p. 36). A major similarity between basic needs and basic capabilities – and which differentiates them both from utilitarianism – is that they rely on resources/functionings rather than upon income which is only relevant insofar as it enhances capabilities or can be used to meet needs. Indeed, Alkire (2002b, p. 163) links basic capabilities and basic needs very specifically: she defines a basic capability as „a capability to meet a basic need.".

Stewart (1996) has undertaken an extensive analysis of the differences and similarities between a basic needs and basic capabilities approach and concludes that they would come to broadly similar conclusions in the poorest countries. However, a basic needs approach would strongly emphasise public provision of goods, particularly in its most elemental basic goods incarnation, but would not privilege differences in personal characteristics, whereas the basic capabilities approach puts a strong emphasis on freedom of personal choice and therefore does not prioritise public sector provision. Moreover, there is a major theoretical difference between the two approaches: the ultimate objective of basic needs is to promulgate decent life characteristics (or in capabilities terms, basic functioning) whereas a capabilities approach goes beyond that and aims at enhancing *capabilities*.

Sen has reservations about specifically defining what this means, but Alkire (Alkire, 2002b, pp. 180-181) identifies the following four strategies for safeguarding the freedom and choice that are so central to the capabilities perspective: (1) to identify long-term valued capability goals and strategies; (2) to work in the short term to establish functionings relevant to these goals; (3) to implement a strategy which safeguards negative freedoms (for example, to avoid coerced culturally insensitive immunisation); and (4) to mitigate any reduction in wider capabilities that might occur as a result of expanding basic capabilities.

Sen"s capabilities approach is highly sophisticated, takes account of the breadth and depth of valued human actions and states of well-being and has potential relevance for the whole

of humanity. However, beyond the identification of functionings associated with basic capabilities (all closely related to basic needs) he does not provide a list, or even an indication, of a range of appropriate functionings or of what an ideal or model or typical capability set might look like. In addition, he makes a case for accepting cultural relativity in relation to capability sets – that these may differ from culture to culture rather than being necessarily universal in nature (Sen, 1993).

According to Qizilbash (1998, p. 53) Sen"s reluctance to be pinned down relates to his emphasis on the value of freedom: „Positive freedoms and valuable functions are, for Sen, amongst the chief objects of intrinsic importance. Resources are means to freedom" and „Well-being is part of the idea of valuable functioning, and quality of life should be judged in terms of the ability to achieve well-being."

Robeyns (2003, p. 371) views Sen"s formulation of the capabilities approach as empirically unsubstantial and „still far removed from a mature and well established framework" because it can only be operationalised at the most urgent extreme of absolute poverty. Gasper (Gasper, 2002) puts forward a more ontologically substantive critique, claiming that Sen does not have a strong conception of „personhood" which results in a thin and unduly individualistic analysis of well-being.

Alkire (2002b) attempts to deal with Robeyns" critique by evaluating three development case studies from an operationalised capabilities perspective. In doing so she identifies „basic human values" derived from „reasons for acting which need no further reasons", based on what is self-evidently true (Alkire, 2002a, p. 185). These values emerge from an iterative process of continually asking: Why do I do what I do? Why do others do what they do? The resulting list is intended is intended to give an account of all the basic purposes of human actions:

- life itself – health and safety;
- knowledge and aesthetic experience;
- (excellence in) work and play;
- friendship;
- self-integration (inner peace rather than inner conflict);
- self-expression or practical reasonableness (harmony among one"s judgements, choices and performances);
- religion (peace with a „more than human" source of meaning and value.

This list, although wide ranging, is sparse and not over-specified, in order to retain choice (Alkire, 2002a). For her the ultimate goal is „equality in persons" capability to meet their basic needs that does not comprise their capability to enjoy non-basic valuable beings and doings" (Alkire, 2002b, p. 195). The above list is not universally accepted however. Gough (2004a, p. 294) reports from a review of participatory studies researching the priorities of members of poorer communities in developing countries that one of the above items, knowledge, is „not in general considered as good *in itself* as a basic human value but only instrumentally so in relation to the impact the knowledge has upon life chances."

Nussbaum's approach – capabilities

There is another, more comprehensive formulation of the capabilities approach than Sen"s which is focused more strongly on moral imperatives than on freedoms and choice. This is the universalistic capabilities approach, as expounded by Martha Nussbaum, which, according to Gasper (1997, p. 299) „gives a rich picture of what is a full human life, and talks in terms of real people, real life, and not thin abstractions."

There are four areas where Nussbaum develops Sen"s capabilities approach. First, she argues for objective universal norms of human capability across cultural boundaries which therefore are not constrained by cultural relativism. For her, „the good life is non-relative – in that it is invariant across classes, societies and cultures" (Qizilbash, 1998, p. 56). Second, her account of the good human life is singular: she demands an account that „should preserve liberties and opportunities for each and every person, taken one by one, respecting each of them as an end" (Nussbaum, 2000, p. 55). Third, Nussbaum is explicit about the functionings that make up a distinctively good life which for her are based on Aristotelian foundations of being organised by practical reason and which takes shape around other-regarding affiliations, „so, for Nussbaum, the good life is the life of the correct choice of action" (Qizilbash, 1998, p. 55). Finally, Qizilbash states that she distinguishes „those capabilities for functioning that are to do with the individual"s personal constitution from the external conditions which facilitate the exercise of such capabilities" (Qizilbash, 1998, p. 55).

Nussbaum"s approach to capabilities is perhaps more unequivocal than Sen"s, even at the basic capabilities level. She takes a similar stance to basic needs in insisting that the central goal is to get *everyone* above the threshold – that is, to achieve an initial „capability equality" – and that until this is done, those inequalities above the threshold can only be tolerated so long as they move more people across it. Once *all* are across the boundary then, from Nussbaum"s perspective, societies should be free to choose other goals. But even these goals, according to her formulation, have to be consistent with all humans having an equal opportunity to achieve a „good" human life, which, from her Aristotelian perspective, means „to do well and live a flourishing life" (Nussbaum, 1995, p. 81). Further to this, Nussbaum states the following:

> *In certain core areas of human functioning a necessary condition of justice for a public political arrangement is that it delivers to citizens a certain basic level of capability. If people are systematically falling below the threshold in any of these core areas this should be seen as a situation both unjust and tragic.* (Nussbaum, 2000, p. 5)

Her most tangible difference from Sen is that she provides an extensive list of central human functional capabilities as a basis for determining a decent social minimum in a variety of areas (Nussbaum, 2000). The version of the list given below is derived from two lists developed by Nussbaum (1995, p. 81; , 2000, pp. 78-80).

1. *Life*: being able to live to the end of a normal human life.
2. *Bodily health*: being able to have good health, including reproductive health; nourishment; shelter.
3. *Bodily integrity*: being able to move freely; having bodily boundaries (i.e. secure against assault); having opportunities for sexual satisfaction and choice in reproduction.

4. *Senses, imagination and thought*: freedom of use and expression of all three, including politics and religion [all informed and cultivated by education] – and pleasure and avoiding non-necessary pain.
5. *Emotions*: to be able to feel them and not for them to be blighted by fear, anxiety, abuse or neglect.
6. *Practical reason*: being able to form a conception of the good and to engage in critical reflection – including the use of conscience. [Being able to plan one"s life, seek employment and participate in politics].
7. *Affiliation*: to be able to interact, show compassion, to have friendships. Protection against discrimination and enabling of dignity, self respect.
8. *Other species*: being able to live with concern for and in relation to animals, plants and the world of nature.
9. *Play*: being able to laugh, play and enjoy recreation.
10. *Control over one's environment*: political – effective participation; material – being able to hold property on an equal basis with others and to have equal access to employment. [Being able to live one"s life in one"s own surroundings and context, i.e. guaranteed freedom of association and freedom from unwarranted search and seizure. Freedom of assembly and speech].
11. *Being able to live one's life and nobody else's:* i.e. non-interference with choices over marriage, child bearing, sexual expression, speech and employment.

Nussbaum claims that there is component pluralism and irreducibility in her list, and furthermore, a lack in any one of them leads to a shortfall in „a good human life." Practical reason and affiliation (items six and seven) are particularly significant for Nussbaum. She identifies „spheres of human experience that figure in more or less any human life and in which more or less any human being will have to make some choices rather than others" (Nussbaum, 2000, p. 72). For Nussbaum a human being is a „dignified free being who shapes his or her life in co-operation and reciprocity with others…a life that is truly human is one that is shaped throughout by these human powers of practical reason and sociability" (Nussbaum, 2000, p. 72).

Nussbaum"s approach to human capabilities is not without its critics however. Gough (2004a) views the foundations of Nussbaum"s approach as „shaky" and its potential for securing cross-cultural consensus as unproven and „probably weak". Qizilbash is also critical of Nussbaum"s approach: „Nussbaum leaves her conception of the good "vague" so that it is open to "plural" specifications by different people and particular "local" specifications in different contexts." He claims „vagueness" just won"t work: in an Aristotelian view there is only one good life and this just is not compatible with pluralism (Qizilbash, 1998, p. 56).

Conclusion

Four approaches to quality of life have been presented here: utility; needs; prudential values and capabilities. Utility is the simplest and the most easily implemented. It is the simplest in that it is monistic: it has a central overriding conceptual theme of the absolute importance of mental states or pleasure or happiness (or utility). It is operationalised through the expression and meeting of people"s actual desires which reflect these mental states of happiness, and it is measured, at least in relation to desires for goods and services, by price. It can be summatively measured in terms of income. Utility is individualistic in nature. All the other constructs mentioned here are underpinned by social concerns, commencing with

social notions of decency, moving through to prerequisites for participation and culminating with universal norms and values.

Needs are also relatively straightforward, at least in their most modest formulation as, by definition, basic needs are necessities of life. They can be identified in terms of the provision of resources to provide minimum threshold standards for a decently acceptable life in terms of nutrition, shelter, basic health services and a basic level education (generally regarded as basic literacy). Doyal and Gough provide a wider, more complex and more sophisticated theory of human need. Their THN starts with the absolute necessities of avoiding serious harm and the ability to participate. From this they derive two primary needs of physical health and autonomy of agency. The latter is achieved when people can make informed choices in their lives. The THN goes much further than basic needs in its stipulation of eleven intermediate needs which have to be fulfilled to meet the two primary needs. The intermediate needs cover all areas related to basic needs but also include such wider-ranging items as significant primary relationships and safe birth control and child-bearing. Doyal and Gough insist that the THN, although wider than basic needs, is still parsimonious and rigorously derived from first principles in order to provide „the lowest common denominator of universalisable preconditions for human action" (Gough, 2003, p. 16). The other needs-based formulation discussed here is the human development index which can be seen to some extent as a hybrid with utilitarianism in that it includes a national income measure, GNP, as well as life expectancy and literacy.

Prudential values are more complex and less clear-cut than either utilitarianism or needs. Their starting place, like utilitarianism, is with desires but not *actual* desires which are seen as being too fallible. Instead *informed* desires are the basis for a recipe for making „any human life better". The epistemological foundations of prudential values lie in the nature of a *characteristically human life* which relates to the essential intersubjectivity and mutual intelligibility of human beings. Again, like utilitarianism, the core of prudential values lie in pleasure and its opposite, pain. Some of the other prudential values cover the same areas as does the THN, while others deal with more „heavyweight" aesthetic and aspirational values. Prudential values are not clear-cut because no definitive list has yet been provided but its proponents claim that this is not a problem in that it encourages the construction of a range of lists via a process of prudential deliberation about what makes a characteristically human life go better. It is assumed that because of our shared human values, such deliberations would result in these lists having considerable similarities.

Thus, a major difference between prudential values and needs-based approaches is that the latter have closed rigorously defined lists whereas in the former there is the opportunity for the exercise of freedom in compiling lists. Sen's capabilities approach shares this strong valuation of freedom. Indeed, capabilities, according to Sen, are to do with the freedom to pursue valuable „doings" and „beings" in order to flourish as a human being. „Flourishing" here includes pleasure and enjoyment so has resonances with both utilitarianism and prudential values. There is also a version of capabilities that is similar to prudential values: the „basic capabilities" approach covers the same substantive approach as basic needs but has more flexibility.

Due to his insistence on freedom, Sen refuses to provide a list of capabilities beyond this basic level. Therefore he gives no substantive account of the „good life". More pertinently, he accepts the likelihood of there being cultural differences in capability sets between cultures.

Nussbaum‟s approach to capabilities takes on board Sen‟s structure of beings and doings but is predicated on a more tightly knit and „thick‟ version of flourishing based on the „correct‟ choice of action. Her version of capabilities then, does not allow for cultural relativity. It is both universal and singular and, unlike Sen‟s, does have a list of central human functional capabilities. Her list covers all the areas dealt with by prudential values and THN, but also stresses the value of play and of respect for other species. Gough (Gough, 2004a, p. 293) states: „Our theory of human need perhaps sits between the Sen and Nussbaum approaches‟ and Gough (Gough, 2004b, p. 18) effectively summarises the similarities between these perspectives as follows: „Despite differences between the work of Sen, Nussbaum, Doyal and Gough and others the upshot is a non-monetary and multi-dimensional concept of human needs, functions and well-being.‟

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