

## The Bradford Well-being Profile



Bradford Dementia Group  
Division of Dementia Studies

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# The Bradford Well-being Profile

## Introduction

The Bradford Well-being Profile is a tool to enable practitioners to monitor how individual people with dementia are faring psychologically and socially. In its original form, well-being profiling provided a way to observe and record what were known as indicators of well- and ill-being. We now refer to these as positive and negative behavioural indicators. These behavioural signs are seen as evidence of a person's positive and negative experiences which, taken together, create their overall experience of well-being. The positive indicators are characterised by signs that people are engaging with the world around them and experiencing positive feelings. The negative indicators are characterised by signs that people are withdrawing, or disengaging, from the world around them and experiencing negative feelings. On the negative side, we also consider risk factors likely to undermine well-being.

Monitoring well-being is of limited value unless followed up with appropriate action. People with dementia need social and emotional care as well as physical care, and the all-important step that should always follow a Well-being Profile is discussion of social and emotional needs and how to meet them. Ideas for action can be included in care plans. These can include measures to ameliorate or avoid negative feelings and withdrawal, as well as actions to support or enhance positive feelings and engagement.

## Background to the Bradford Well-being Profile

The Bradford Well-being Profile grew out of Dementia Care Mapping. Dementia Care Mapping (Brooker and Surr, 2005) is a method that uses continuous observation to gain a picture of the activities and well-being of people with dementia. The early versions of the Bradford Well-being Profile were produced in response to the demand for a relatively quick and easy way for caregivers to monitor the well-being of individual clients in their care on an ongoing basis.

The Well-being Profile is based upon behavioural indicators developed by Kitwood and Bredin (1992) used in Dementia Care Mapping. Previous versions of the Well-being Profile had a simple scoring system. The psychometric work we have done suggests that well-being scores have some validity if problems with inter-rater reliability are addressed, but that ill-being scores do not. Given that inter-rater reliability is likely to be a problem, and that scores are not always interpreted with sufficient caution, we have now dropped the scoring system (see reliability and validity). For monitoring individuals over time and providing good care, it is much better to work with profiles than attempt to use a numerical score. Profiles provide a qualitative picture, which gives us more clues about what can be done.

The Well-being Profile relies on observation to monitor well-being, but we now have a considerable body of evidence suggesting that many people with dementia can tell us about their experiences (Keady, 1996; Sabat, 2001; Harris, 2002) and can report on their own quality of life meaningfully (Mozeley et al, 1999). Asking people to comment on their own well-being can provide additional evidence when compiling a Well-being Profile. This is likely to be easier for people with mild to moderate dementia, but even those with severe dementia may be able to comment to some extent.

## Uses of the Well-being Profile

Well-being profiling can be used to:

- Monitor how individuals with dementia are faring over time;
- Provide a framework and a language for carers to think and talk about the social and emotional needs of people with dementia;
- Base assessments of social and emotional needs on careful observation and listening to what people have to say;
- Underpin care plans addressing social and emotional aspects of care.

Well-being profiling is not well suited for use as an outcome measure in quantitative intervention studies, nor for measuring changes in mood during an intervention.

## Who should use the Well-being Profile?

You do not need to be trained as psychologist or nurse to make good use of the Well-being Profile. Whatever your training or background, you should be familiar with the person-centred approach to dementia and guided by this when using the profile. In particular you need to have an understanding of the principles of person-centred care, the mental states thought to underpin well-being (Kitwood, 1990) and the psychological needs of people with dementia (Baldwin and Capstick, 2007). There are some notes on taking a person-centred approach in the section 'How to use the Well-being Profile.'

## What do we mean by well-being?

We all have fluctuations in mood as we go through life. There are bad times and good times, ups and downs. Well-being is an estimate of how a person experiences life overall, taking into account the ups and downs (Diener and Larson, 1993). It is a judgment of how a person is faring, given all that is happening to them and how they feel about it. Living with dementia not only presents a challenge to well-being, it can also undermine the personal and social resources needed to cope with difficult situations. For these reasons, many people with dementia need help from caregivers if they are to maintain well-being.

## How can we influence well-being?

We can influence well-being by looking at a person's profile of ups and downs and thinking about their needs and how they can be met. We cannot move mountains, but little things can make a difference. Care planning can consider how to:

- Support situations that lead to positive behavioural signs recorded as 'strong' on the profile (e.g. social contact, warmth and affection);
- Promote situations that might generate positive behavioural signs recorded as 'weak' on the profile (e.g. humour, helpfulness);
- Respond to negative behavioural signs (e.g. pain, distress, boredom) in a comforting way;
- Avoid situations that generate negative behavioural signs;
- Minimise the effects of factors that put well-being at risk.

## Patterns of well-being

There are different ways in which well-being can be high or low. Each person's profile will be made up of a different combination of positives and negatives, and their overall experience of well-being will vary as a result of different combinations. Although each person is unique, it can be useful to look out for common patterns.

### ***High well-being***

#### **High on positives, low on negatives**

Those experiencing many positives and few negatives may be described as 'sunny natured', 'sparky', 'optimistic', 'buoyant'. Experiencing just a few positives is often enough to maintain a reasonable level of well-being if someone is low on negatives. People are described as 'contented', 'uncomplaining', 'easy-going' 'no trouble'.

#### **High on positive, high on negatives**

Experiencing both strong positives and strong negatives leads to mood swings, and people are described 'intense' 'emotional' 'unpredictable'. If the positives and negatives are fewer and weaker, people are described as 'a bit up and down' 'changeable'. If the positives predominate, these people may have high well-being, especially if coping with intense lows has been a lifelong experience, and they are given support when in the grip of difficult feelings.

### ***Low well-being***

#### **Low on positives, low on negatives**

Experiencing both few or no positives and few or no negatives is associated with disengaging from the world, and suggests that someone is withdrawing. People are described as 'unresponsive', 'faded', 'hard to reach' 'a shadow' 'vague'.

#### **Low on positive, high on negatives**

Experiencing many negatives and few positives puts people into a very uncomfortable state. People are described as gloomy, pessimistic. If the negative experiences are intense and positives absent, people are described as 'desperate', 'without hope', 'despairing', 'living in a nightmare world'.



Example of a Well-being Profile and Action Plan
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<b>BRADFORD WELL-BEING PROFILE - POSITIVES</b>		<b>Date:</b> 27/11/07
<b>Name:</b> Ruth McBride	<b>Observers:</b> Jill Duncan Karen Lewis Maggie Hughes	

<b>Positives - strong on</b>	<b>Notes</b>
Alertness, responsiveness	Responsive to staff.
Responds appropriately to people/situations	Tuned into staff. Keeps her distance from other residents.
Self-respect	Likes to be clean and tidy.
Co-operative and helpful	When asked – does not initiate.
Shows pleasure and enjoyment	Subtle signs when with staff, or when Margaret comes.
Shows warmth and affection	Only to staff she likes - and Margaret.

<b>Positives - weak on</b>	<b>Notes</b>
Can communicate wants needs and choices	When asked. Does not initiate.
Making contact with others	Responds to staff who make contact with her. Avoids contact with other residents. Seldom initiates contact with anyone.
Sense of purpose	Very passive.
Sense of humour	Usually serious. Occasional twinkle when Margaret here.
Using remaining abilities	Only when given one-to-one encouragement.
Relaxed posture/body language	Only when in close contact with staff or Margaret, or when in bed.
Expressing appropriate emotions	Only a few staff feel that they know what she is feeling. Most find her hard to read.

<b>BRADFORD WELL-BEING PROFILE - NEGATIVES</b>		<b>Date:</b> 27/11/07
<b>Name:</b> Ruth McBride	<b>Observers:</b> Jill Duncan Karen Lewis Maggie Hughes	

<b>Negatives - strong/ high risk</b>	<b>Notes</b>
Shows anxiety or fear	Often looks a bit worried when staff not near. Gives others a wide berth if they are sounding off, looks scared. We think she often 'freezes' when frightened, rather than going for 'flight or fight.'
Tense body	Often looks tense when not with staff member or Margaret.
Bored	Seems to have very boring life.
Lack of activity/stimulation	Only joins in with activities if someone takes her to join in.
Listless/withdrawn	Not listless, but she does seem to withdraw.
Easily 'walked over' by others	Does not stick up for herself – keeps away from others. We think she is frightened of them.
An outsider (feels/is different from others)	We think she probably feels different from others, but she could just be shy and nervous of other people she doesn't feel she knows very well.
Has physical discomfort or pain	Has arthritis so probably has aches and pains. Sometimes winces.

<b>Negatives – weak/ low risk</b>	<b>Notes</b>
Agitation, restlessness	At times she might feel agitated but freezes, so it is not obvious in her behaviour.
Anger, frustration	Mild, doesn't show anger. Doesn't show frustration. Gives up easily.
Depression/despair	Could be a little depressed, hard to tell. Should have a proper assessment for depression.
Sadness/grief	No obvious signs.
Disliked/feared by others	No signs of this. Others don't take much notice of her.
Past trauma resurfacing	No known trauma. No signs of frightening memories from the past resurfacing.

<b>BRADFORD WELL-BEING PROFILE - NEEDS AND ACTION PLANS</b>		<b>Date:</b> 27/11/07
<b>Name:</b> Ruth McBride	<b>Observers:</b> Jill Duncan Karen Lewis Maggie Hughes	

<b>Needs</b>	<b>Action plans</b>
To be helped to communicate wants, needs and choices	Make a point of asking her what she wants. Remember to give her choices e.g. what she would like to wear.
To feel less anxious and more relaxed	Invite her to sit near staff. Give her support when others are sounding off.
To connect with other residents, encourage a sense of belonging	Encourage one-to-one contact with people like Joan and Betty. Introduce her to people. Take her to sit with people and help to get conversation and communication going. Look at ways to get her doing things with other people.
To be more active	Ask Margaret what her interests were. Remember to take her to join in when activities are going on. Involve her in one-to-one activities or activities with one or two other people.
To be encouraged to use remaining abilities	Find little things she can do to help e.g. she can take notes to the office. She can put beakers on the trolley after meals.
To check on pains	Ask if she has aches and pains. Investigate when she winces. Record and review.

Ruth McBride lived in a care home and had no family. Her friend Margaret visited once a week. Before profiling, staff had assumed that she was a bit of loner, happy in her own company.

After profiling, they felt that she was less content and more anxious than they had previously thought. They realised that she needed more support, both to cope with her fears and anxieties, and to enable her to have more positive experiences. They felt that she would benefit if she could make friends with one or two of the other residents.

## How to use the Well-being Profile

The Well-being Profile was designed for people taking a person-centred approach to dementia care. The following section explains what this means.

### Taking a person-centred approach

The starting point of the person-centred approach is to acknowledge the rights and needs of people with dementia. Brooker's (2004) principles of person-centred care explain what this means in practice.

#### Principles of person-centred care (VIPS) (Brooker, 2004)

- 1 We value people with dementia and take their experiences seriously, regardless of age and cognitive impairment.
- 2 We treat people as individuals, appreciating how their personality, life history, health status and social environment along with cognitive impairment shape their experience of dementia.
- 3 We recognise that each person's experience has its own psychological validity, and make efforts to understand their perspective.
- 4 We recognise that relationships are important to people with dementia, and understand that they need for a supportive social environment which compensates for disabilities and fosters well-being.

Dementia and all that comes with it is a big threat to well-being, but it is possible for people with dementia to experience well-being if they are living in a supportive social environment.

#### The underpinnings of well-being (Kitwood, 1990)

##### **Self-worth**

Does the person expect to be respected and taken seriously?

Does the person feel they matter?

Do they expect their fair share?

##### **Sense of agency**

Does the person have the feeling that they can make things happen?

Do they have a sense of control?

##### **Sense of hope**

Does the person feel that things will turn out alright in the end?

Are they free from the feeling that life is hopeless?

Are they free from persistent, feelings of grief, anger, anxiety, depression etc.?

##### **Social confidence**

Is the person able to initiate contact with other people?

Can they be relaxed in company?

Are they able to hold their own with others?

Dementia is a disabling and life-changing condition. We can do a lot to help people cope with the experience of living with dementia. We can start by understanding their psychological needs. The person-centred approach is about taking these needs seriously and finding ways to meet them.

The psychological needs of people with dementia (Kitwood, 1997)

**Identity**

Does the person appear to have strong sense of self?  
Do they have a positive sense of self?  
Do they have a sense of continuity between past and present?

**Comfort**

Does the person receive the comfort they need for their emotional distress?  
For example, when angry and frustrated; anxious and agitated;  
depressed and hopeless; listless and withdrawn?

**Attachment**

Does the person have someone they feel close to and can rely on and trust?  
Do they have someone to turn to when they are distressed?  
Do they have continuing bonds with people who have died? (e.g. act as if mother is still alive, or re-create the feeling of closeness to a significant people by talking about them, or to them.)

**Occupation**

Does the person feel they have something meaningful to do? (This could come from feeling that they have work to do, involvement in daily life or watching the world go by)  
Are they sufficiently free from anxiety to be able to engage with activities?  
Do they experience feelings of boredom and apathy?

**Social inclusion**

Does the person have a sense of belonging?  
Do they feel at home and fully included in social groups?  
Do they feel left out, excluded, or that they don't fit in?

## Planning and preparation

- Choose observers (it is a good idea to have more than one person)
- Decide on the period of observation (at least a week)
- Make sure observers are familiar with the guidelines on the positive and negative indicators
- Discuss the tips for observation and interpretation (below)
- Set a time to meet, discuss observations and fill in the profile forms at the end of the observation period.

You need accurate, up-to-date observations of behaviour and thoughtful, sensitive judgements about what this behaviour means to fill in a Well-being Profile.

### ***Tips for observation***

- Keep an open mind;
- Familiarise yourself with the positive and negative indicators;
- Be on the look out for the positive and negative indicators during the observation period;
- Be on the look out for the unexpected as well as ordinary, unremarkable behaviour;
- Be aware of your own bias (for example, it is very common to think that rare but frightening incidents are occurring more frequently than they are because they are so memorable);
- Refer to the guidelines on the positive and negative indicators when filling in a profile.

### ***Tips for interpretation***

Interpretation should be guided by the understanding and skills central to the person-centred approach. Start by assuming that:

- There is sense in what people with dementia say and do;
- People are likely to be more aware of their surroundings than they seem;
- People with dementia have feelings about what is happening to them, they try to manage their feelings in various different ways (e.g. denial, blaming others for mistakes);
- Feelings are not always expressed directly and obvious manner;
- Feelings are often expressed in behaviour.

Use your emotional intelligence and empathic skills to put yourself into the shoes of each person with dementia, and to imagine how things look and feel to them.

## Guidelines and forms

### Positive behavioural indicators – guidelines

**1. Can communicate wants, need and choices.** The person can communicate what they want or need, verbally or non-verbally. They can use words or gestures (or both) to get across what they want or do not want. They can challenge someone who is trying to get them to do something they do not want to do. Aggression provoked by the experience of receiving care (e.g. being told what to do or by feeling frustrated and powerless) can be seen as a sign of being able to communicate wants, needs and choices. (However see also ‘anger and aggression’ under ill-being.) Silence or inactivity can communicate reluctance, fear, pain, disapproval, confusion etc.

**2. Makes contact with other people.** The person attempts to make contact with other people, for example by talking, making sounds, waving, touching, using gestures, making eye contact, winking, leaning forwards, holding hand out. It is not necessary to be able to talk to make contact with others. The person is able to initiate contact as well as respond to others.

**3. Shows warmth or affection.** The person shows signs of warmth or affection towards other people, and is responsive when others are warm or affectionate with them. Warmth or affection can be directed at visitors, caregivers, animals, dolls or people not actually present such as a dead spouse or absent family members. Words of endearment such as ‘like’, ‘love’, words of positive regard such as ‘nice’, ‘pretty’, ‘lovely’, ‘good’, ‘great’ and words of gratitude such as ‘thank you’ are signs of warmth. Also look out for sounds (e.g. cooing and chuckling) and gestures (e.g. holding hands, hugging, stroking, patting, smiling, gazing, kissing, blowing kisses and holding). Also be on the look out for ‘a fond look in the eyes’, looking bright eyed or animated when a person is present; tracking a person’s movements with the eyes; disguised or ‘rough’ affection shown by gestures like slapping someone on the back.

**4. Shows pleasure or enjoyment.** The person shows signs of pleasure, enjoyment or happiness in the course of ordinary every day life, for example in response to food and drink, social contact and the sights, sounds and smells of the world around them. Examples: enjoying a good meal, giving a contented sigh when tucked into bed, looking bright-eyed and alert when an entertainer is performing, looking relaxed and dreamy during a hand massage, smiling at a visitor.

**5. Alertness, responsiveness.** The person responds to their surroundings. They react to an unexpected noise or movement, or can be seen to be watching things that are happening. Different people will be alert to different things e.g. watching other people, looking birds or plants outside the window, noticing features of the building, looking at TV, listening to music. Careful observation is needed to distinguish between vacant staring and someone who is watching the movement of leaves on a tree, or particles of dust in a sunbeam. People with severe dementia may only be responsive to things in their immediate vicinity.

**6. Uses remaining abilities.** Given appropriate stimulus and encouragement, a person responds to their environment making use of retained abilities. Examples: a person who is able to speak uses speech when spoken to, someone who can walk will walk, someone who can sing will join in when others are singing a favourite song.

**7. Creative expression.** There is scope for creative expression in many activities, but not all activity is creative. When a person is putting something of him/herself into whatever they are doing, rather than doing it in a 'let's get this over and done with' manner, it will count as creative expression. In particular, music, dancing, visual arts provide opportunities for creative expression.

**8. Co-operative or helpful.** The person volunteers help, is willing to help when asked or co-operates when others are helping them. What is important here is willingness to help or co-operate, rather than outcomes. Some attempts to help may not actually be helpful, but the attempt or intention to help or be co-operative is what counts.

**9. Responding appropriately to people/situations.** The person shows awareness of other people's needs or feelings. Examples: moving out of the way to let another person past, giving a hand to someone who needs support, showing concern for someone who is distressed.

**10. Expresses appropriate emotions.** The person shows emotion in line with their personality. Examples: sadness when a visitor leaves; tears when remembering that someone they cared for is dead; elation after an argument; anger when someone treats them badly; frustration when they try to do something and can't; irritation when others are annoying; boredom when there is nothing to do.

**11. Relaxed posture or body language.** The person has times when they are both alert and relaxed, with a calm facial expression and without repetitive movements. Times of blank withdrawal, when alertness is lost, do not count.

**12. Sense of humour.** The person expresses a sense of humour, with jokes, comments or actions, or responds to the humorous comments or actions of others with smiles or laughter. This can include laughter when something goes wrong – e.g. a caregiver drops a box of dominoes.

**13. Sense of purpose.** The person shows that they feel able to make things happen, or have something to contribute. They undertake real or pretend work. Examples: making the movements of cleaning; carrying a bag with a purposeful expression; rummaging in a cupboard; removing cups from the table; helping someone out of a chair.

**14. Signs of self respect.** The person shows signs of trying to preserve dignity, modesty or self-respect. Examples: Adjusting clothing, taking pleasure in grooming, wiping up spilt food, not wanting to participate in a game because they think it is childish. Resisting help with private matters like toileting; refusing to co-operate when treated in a bossy or patronising manner or reacting angrily to other personal detractions can count as self-respect.



<b>BRADFORD WELL-BEING PROFILE</b>		<b>Date:</b>
<b>POSITIVE INDICATORS</b>		
<b>Name:</b>	<b>Observers:</b>	

***N.B. Please remember to use the guidelines to help you make your judgments***

<b>Positive indicators</b>	<b>Strong</b>	<b>Weak</b>
1. Can communicate wants, needs and choices		
2. Makes contact with other people		
3. Shows warmth or affection		
4. Shows pleasure or enjoyment in daily life		
5. Alertness, responsiveness		
6. Uses remaining abilities		
7. Creative expression (e.g. singing, dancing)		
8. Is co-operative or helpful		
9. Responds appropriately to people/situations		
10. Expresses appropriate emotions		
11. Relaxed posture or body language		
12. Sense of humour		
13. Sense of purpose		
14. Signs of self-respect		

<b>BRADFORD WELL-BEING PROFILE - POSITIVES</b>		<b>Date:</b>
<b>Name:</b>	<b>Observers:</b>	

<b>Positives – strong</b>	<b>Notes</b>

<b>Positives – weak</b>	<b>Notes</b>

## Negative behavioural indicators and risk factors

### ***Behavioural indicators***

**1. Pain, physical discomfort.** The person reports pain or discomfort, or there are non-verbal signs such as fidgeting, grimacing, wincing, sighing, holding or rubbing. Pain may be linked to other negative signs such as aggression, anxiety and agitation. It is important to remember that physical discomfort, stiffness and pain are all common in older people. Not being in constant pain is not a reason to dismiss pain as unimportant.

**2. Tense body.** Tight muscles in face or any other part of the body.

**3. Agitation, restlessness.** The person moves a lot, and in a manner which suggests that they are upset, anxious or uncomfortable rather than purposeful.

**4. Anxiety, fear.** The person reveals anxiety or fear in what they say, their facial expressions, other body language and behaviour. There are a range of instinctive responses to fear which include aggression (fight), running away (flight), staying very still (freeze) and seeking safety in numbers (flock). Also, the attachment system may be activated, in which case the person will seek out an attachment figure to protect them and reassure them. In childhood this is typically mother, and the need to find mother (or father) when alarmed often resurfaces in people with dementia.

**5. Anger, frustration.** The person expresses a great deal of anger and frustration. Anger erupts without warning and is persistent. Their anger is very easily triggered and is not necessarily a reaction to what is happening (e.g. resisting personal care) or what the person believes is happening (e.g. believing that someone is attacking them.)

**6. Depression, despair.** The person shows several signs of depression such as low mood, lack of interest in usual activities, being unresponsive to pleasant events, being irritable, having multiple physical complaints, loss of appetite, difficulty falling asleep, early waking, disturbed sleep, suicidal thoughts, pessimism, poor self-esteem, negative outlook, symptoms worse in the morning.

**7. Sadness, grief.** The person is persistently sad and grieving.

**8. Listlessness, withdrawn.** The person is frequently unresponsive, and seems to be blank and withdrawn. There are no signs that they are day-dreaming, or occupied in their own mind. Even when given long periods of sustained attention (e.g. 15 minutes) they do not respond.

**9. Boredom.** The person indicates verbally or non-verbally that they are bored.

## **Risk factors**

**10. An outsider (feels/is different to others).** The person has reason to feel different to the group they are in for any reason (e.g. the only man in a group of women, a Londoner in the Highlands, an Anglican in a Catholic facility, the only homosexual). Comments or jokes about a person's difference, though friendly in tone, may be undermining.

**11. Easily 'walked over' by others.** The person finds it hard to hold their own in a social group. Ways of coping may include being quiet and unassertive, avoiding dominant individuals.

**12. Disliked/feared by others.** The person is disliked or feared by other users who may keep away or make unfriendly comments. If they are disliked or feared by staff as well, they may be very socially isolated.

**13. Lack of activity/stimulation.** The person is not helped to find occupation, lacks appropriate stimulation and is therefore leading a very a dull life.

**14. Trauma and unhappy past experiences.** The person has had traumatic or unhappy experiences. These may influence how they are experiencing their present situation, with memories of the past mingling with perceptions of the present. For example, a nursing home can be confused with a concentration camp, prison, boarding school or hospital. Caregivers with a tough manner or similar characteristics to frightening figures from the past can be mistaken for punishing policemen, teachers, soldiers, jailors, bogeymen or parents.

<b>BRADFORD WELL-BEING PROFILE</b>		<b>Date:</b>
<b>NEGATIVE INDICATORS</b>		
<b>Name:</b>	<b>Observers:</b>	

***N.B. Please remember to use the guidelines to help you make your judgments.***

<b>Negative indicators</b>	<b>Strong</b>	<b>Weak</b>
1. Pain, physical discomfort		
2. Tense body		
3. Agitation, restlessness		
4. Anxiety, fear		
5. Sustained anger, intense frustration		
6. Depression, despair		
7. Unresolved sadness, grief		
8. Listlessness, withdrawn		
9. Bored		
<b>Risk factors</b>	<b>High risk</b>	<b>Low risk</b>
10. An outsider (feels/is different to others)		
11. Easily 'walked over' by others		
12. Disliked/feared by others		
13. Lack of activity/stimulation		
14. Past trauma/unhappy experiences		

<b>BRADFORD WELL-BEING PROFILE - NEGATIVES</b>		<b>Date:</b>
<b>Name:</b>	<b>Observers:</b>	

<b>Negatives - strong/high risk</b>	<b>Notes</b>

<b>Negatives - weak/low risk</b>	<b>Notes</b>

<b>BRADFORD WELL-BEING PROFILE</b>		<b>Date:</b>
<b>NEEDS AND ACTION PLANS</b>		
<b>Name:</b>	<b>Observers:</b>	

<b>Needs</b>	<b>Action plans</b>

## Reliability and validity

### Reliability

Well-being is similar to other psychological attributes, in that we should not expect to measure it with the same accuracy as temperature or weight. However, there are particular reasons to think carefully about the reliability of our judgments when considering the well-being of people with dementia. For example:

- The signs of well-being may be different, depending upon a person's social environment. As observers are part of the social environment, they will be an influence on the attribute they are observing. (As Kitwood (1997) emphasised, the well-being of a person with dementia is influenced by how other people treat them as much as it is by their internal psychological characteristics.)
- The well-being indicators were designed for use by people with a good understanding of the person-centred approach to dementia. People who do not take this approach often have different assumptions about what people with dementia are experiencing.
- Behavioural signs are open to interpretation. Observers with the same view of dementia may well disagree.

However, we can take steps to produce good estimates of well-being. This can be done by:

- Being alert to sources of bias;
- Giving training those who profile well-being;
- Checking the guidance notes;
- Involving several people in the process.

If well-being is being monitored over time, it makes sense to involve the same people on each occasion. In assessing well-being the process (observing, reflecting, discussing) can be as important as the product (the profile). Even when the people involved disagree about a person's well-being and needs, the process of observing a person, thinking about their needs and discussing what might be done to meet them will give them a greater awareness of the person and their care needs.



## Validity

We have done some psychometric testing on a previous version of the Bradford Well-being Profile which had a scoring system. We found that the ill-being indicators did not meet the criteria for items on a scale. This means that it is not meaningful to calculate an overall ill-being score. We have now divided the negative items into negative behavioural signs and risk factors, adding some further risk factors to the list.

The well-being indicators did meet the criteria for a well-being scale, so it is legitimate to use a scoring system. However, scores need to be interpreted with caution, for two reasons. First, the issues of reliability discussed above. Second, there are problems - often overlooked - that apply to all psychometric measures. These relate to complex mathematical assumptions. A simple explanation is that attributes like well-being may not be quantitative, (in the way that height and weight are quantitative). It is difficult, mathematically, to demonstrate that they are, so this is not usually attempted. The tests of validity conventionally used depend upon making mathematical assumptions that may well be unfounded when measuring psychological attributes like well-being. (Michell, 2006; Kline, 2000.)

These are not reasons to abandon the attempt to monitor well-being altogether, but they are reasons to be cautious about relying on numerical scores. For the purposes of care planning it is better to focus on qualitative profiles, and if numerical score is used it needs to be interpreted with caution. For these reasons we have removed the scoring system.

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