
Carers assessments

Workforce development opportunities based on carers experiences

Research with carers and Carers Trust network partners

April 2013



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Purpose of this report

This research has been commissioned to identify workforce development needs relating to conducting carers assessments. The report includes research to understand the current practices, experiences and potential hurdles/barriers to good experiences of carers assessments for carers. It examines current skills and skills gaps based on consultation with carers themselves and with local carers organisations which are partners in the Carers Trust network.

This work builds on the work done by Skills for Care and Skills for Health “Carers Matter – Everybody’s Business,” which offers resources to enable learning for staff who support carers. This research focusses specifically on the skills required to undertake good carers assessments.

Context

This research is particularly timely in light of the proposals in the draft Care and Support Bill, published on 11th July 2012. This comprehensive reform of social care legislation proposes that, for the first time, carers will be entitled to support to help them with their caring role and to help them balance caring with the rest of their life. All carers will have a right to an assessment to decide if they need support, rather than just those who provide a substantial amount of care. The assessment must be available to all carers and should concentrate on their needs and outcomes and on both their willingness and ability to provide and to continue to provide care. It should also consider whether the carer works, or wants to work, and/or spend time in education, training or leisure time.

These key legislative changes are likely to have significant local impact. Therefore this is an important time to considering workforce development to ensure that those carrying out assessments are well equipped to effectively do so.

Summary of key findings

Although this research has been based on a relatively small sample of carers there are some clear themes that emerge as key priorities to target for workforce development. Perhaps one might have expected that this research would highlight a need for some further improvement in listening skills, empathy and understanding of carers' needs, and indeed these things have been highlighted. However there are also some less obvious findings which are :

Outcome-focused application of knowledge

Perhaps the largest barrier to a successful outcome for carers is the fact that many carers see the process as having no outcome. Areas which are performing well have prioritised having a clear menu of service options available for carers quickly after assessment – which include a mix of social care, health, voluntary sector and community services. Staff therefore need not only to gain the knowledge of what services are available, but be able to apply that knowledge creatively. Developing an outcomes-focused approach will help staff to consider a broad range of ways in which solutions may be reached that meet the needs of the carer, rather than a focus only on more traditional statutory solutions.

Courage to tease out and address difficult issues

Recognition of the challenges and emotions that many carers will face culturally, socially or within their own world view, in considering their own needs or asking for help, is essential for anybody carrying out carers assessments. A patient and painstaking approach to teasing out a situation and seeing behind the everyday coping mechanisms is important. This may be best achieved by starting from the point of recognising and respecting the skills and coping mechanisms that the carer employs and working with the carer to maximise and encourage those while also building on this to identify and address their concerns and struggles. Most carers said that they have no trouble talking about what they can do but real difficulty expressing where they are struggling or need help.

There is also considerable courage and sensitivity needed on the part of the professional to talk through issues such as whether someone is willing or able to continue caring and putting together emergency and future plans.

Clear route map and involvement

Carers feel that they need much clearer communication before, during and after the carers assessment to ensure that they are clear about the purpose of the assessment, the choices available to them and the whole process itself. They also want staff to treat them as experts in the situation of the person with care needs and as adults who are able to make their own decisions and take part in the process in an active way. In particular carers want written follow up that shows the outcome of

the carers assessment and a plan in place about what happens next and how they can feed into the process if they disagree with what is written down or if their circumstances change.

Consultation with carers

Three consultation workshops with carers took place – one in Bath, one in South London and one drawing together carers from a wider area representing members of the National Valuing Families Forum and some carers drawn from Carers Trust network partner organisations. These workshops acted as an opportunity for a depth of discussion about the specific skills and behaviours of professionals conducting assessments that have or would improve carers' experiences. They examined carers' experiences of current practices and aimed to identify potential hurdles/barriers to good experiences of carers assessments for carers.

A total of 25 carers took part. The demographic breakdown of carers who took part is detailed in Appendix 1.

12 of the 25 carers knew they had received a carers assessment. 8 of those 12 carers felt that their carers assessment was more positive than negative and 1 felt it was more negative than positive. The remaining 3 carers felt very mixed.

In two of the workshops carers produced a collage using newspaper cuttings of what they felt represented a good carers assessment and what represented a bad one. These are shown in Appendix 2.

In the sessions discussions focussed around the following questions -

1. What are carers' overall feelings about carers assessments?

For those who knew they had had a carers assessment they generally assessed this more a more positive than negative experience. However, only 2 carers felt that the process was a very positive one, with most feeling more neutral about it as they did not feel that they had experienced a long term positive outcome from it.

Some carers had been offered a carers assessment but had actively turned it down. In one case this was because the carer believed that the assessment was all about her finances and she did not want anyone "prying" into her finances. In another case the carer felt that they may lose their independence and control of their own life if they agreed to a carers assessment. They also felt that that social workers were very busy and they did not want to add to the burden of the social worker as caring was their own responsibility.

Most carers felt that they appreciated the opportunity to have a face to face carers assessment carried out in their home environment and without the person for whom they care present. However, views on both these factors differed and everyone agreed that both where the assessment took place and whether it was in the presence of the person with care needs should be up to the informed choice of the carer.

Almost a third of carers did not know if they had received a carers assessment. Some thought maybe it had been part of a visit from a social worker while something else was taking place, but they weren't sure.

A significant proportion of carers said they felt their social worker was pleasant and had a personable manner with which to conduct an assessment. However, many carers felt this was tempered by a sense that they felt there was an impotence to actually be able to deliver any services that would help and so there was considerable ambivalence about whether there was any point to having a carers assessment. A number of carers expressed concern and feeling sorry for the professionals with whom they have contact; that they seem to be under huge pressure and seem to have little access to enough resources to offer help.

Sadly, one carer can be quoted as saying that she felt, from the way that she was treated, that she was being a "distraction from the social worker's real work."

2. What behaviours and skills from social care professionals contributed to feeling this way or would encourage carers to have an assessment?

The key message here was about receiving a clear explanation about the carers assessment taking place and the opportunity to understand in advance the sort of things that would be discussed and the purpose of the assessment. In only two cases did carers feel they had been offered adequate advance information to understand what the carers assessment would involve and the purpose of it. One carer gave the example that a professional had said to her that she just wanted to come and chat to her. Far from being reassuring, this had left the carer feeling anxious about why the professional was visiting her and whether she had done something wrong.

Carers felt that without clear advance information they were disempowered and "on the back foot." Some expressed that some professionals had tried to explain a carers assessment but had done so in an over-simplified or unclear way. Several carers did not realise that the carers assessment had been to establish their needs as a carer but thought it had been about the care needs of the person they were caring for and there was real confusion among some carers about the distinction between a community care assessment and a carers assessment.

Some carers said that they had appreciated the carers assessment as a “friendly chat” but did not understand what the point of it had been. After hearing from other carers in the group some expressed a wish that they had understood what it was about as this would have helped them to express their difficulties and concerns frankly rather than feeling they just needed to say that they were coping fine.

3. What is important to carers about the way in which social care professionals carried out / should carry out carers assessments? Can different factors be ranked in order of importance?

Before embarking on detailed discussion, carers listed the top 3 things they felt were important about the way in which social care professionals carried out carers assessments. In order of importance to carers these were –

- Coming into the assessment with a good knowledge of options and services available locally
- Employing clear communication before, during and after the assessment – this included using plain English and going over what has been written
- Demonstrating empathy and understanding – this largely focussed around not appearing to just read from a script and tick boxes and making good eye contact.
- Using active listening skills – asking open questions, reflecting back, clarifying things.
- An unhurried approach – carers understood that professionals’ time was limited and did not expect workers to spend a long time discussing unrelated things but did value feeling that the worker was not clock-watching or skimming through discussions in a rush.
- Respecting the carer’s time – being on time, sticking to appointments and deadlines promised
- Treating every carer as an individual – not making assumptions
- Treating carers as an adult and a capable person and recognising their expertise and experience.
- Recognising different cultural and social viewpoints and that for many people the term “carer” doesn’t even feel like it applies to them.

Once this part of the consultation became a deeper discussion it was often the most animated part of the event with carers sharing their experiences, both good and bad. Examples of these are listed in 5 and 6 below.

4. Levels of satisfaction with follow up and support offered after a carers assessment and whether carers feel expected outcomes have been achieved. If so, what skills from social care professionals have contributed to this or would have improved this?

One of the overwhelming themes from all of the workshops was a sense of frustration that there was often no follow up after assessment. The majority of carers felt they had been promised certain actions within certain timescales and in some cases nothing had materialised and in others they had to chase social care staff, often many times, to achieve the agreed outcome or had found out later that things they felt were promised were not possible. The highest level of frustration expressed overall throughout each workshop was about lack of communication after the assessment.

Only 2 carers had ever seen what was written by the professional after the carers assessment and some expressed anxiety about whether the professional had reflected the discussions at the carers assessment accurately.

5. Examples of “Skills for Care Common Core Principles for Working with Carers” being displayed.

Support the mental and physical health needs of carers

A carer described receiving a carers assessment at a time when she was almost at the point of total breakdown. She cares for her husband who is semi-paralysed and has high levels of personal care needs. The carer said that she felt the professional recognised how close to breaking point she was and took quick and decisive action to put in place practical support such as equipment to ease the physical burden of the caring role and counselling to help her with her depression. The carer felt that the worker “took over” in a way that was a total relief at that point and exactly what she needed. Since then she feels she is coping much better and now strong enough to make choices herself but she is very glad that at the time the professional recognised that rapid and meaningful action needed to be taken to maintain the caring role.

Involve carers in making decisions and choices at all levels

A carer who cares for his wife who has MS has appreciated that he has had long standing relationship with the same Social Worker and feels that they work together as partners in the care of his wife. He says that the Social Worker has taken time and listened carefully to find out how he is coping. He feels that he has been given meaningful and informed choices about options for how he gets respite and ensuring he is happy with the replacement care for his wife. He has chosen to administer his wife’s personal budget and feels that this too has contributed to his sense of being in control and able to make choices that both ensure his wife’s care is the best possible and he receives some respite. He describes having a carers assessment as a process that enabled him to feel well informed and more in control rather than feeling left out of decision making.

Recognise and support carers' own needs and aspirations

One participant expressed her gratitude that a professional recognised her interest in yoga, which she finds an activity that gives her a healthy and relaxing break from caring. When a support plan was put in place for the cared-for the timings of respite care were organised to allow the carer to go to her weekly yoga class.

Identify and support young carers

Only three of the carers involved in the consultation had children who were not the person with care needs. In one of these cases, although this was not a part of a carers assessment, the child had been identified as a young carer and their needs discussed by a professional from the local carers centre who was supporting the carer. The young carer had then been linked into the young carers' service provided by the carers centre. This had also proved to be a great relief to the adult carer, who was pleased that there was someone helping her son as she felt guilty that she spent so much of her time caring that she could not give him all she wanted to.

6. Examples of when “Skills for Care Common Core Principles for Working with Carers” have not been experienced and ideas about what would constitute improved service.

Make no assumptions about carers' capacity and willingness to care

Only one carer could recall ever being asked whether they were both willing and able to continue with their caring role and this was not as part of a carers assessment. Carers felt this was an important question (and indeed some knew it was a requirement of a carers assessment) and reflected on how difficult it would be for a carer to say they wouldn't or even couldn't carry on caring. Some expressed a cynicism that the reason they had never been asked was because the professional might not want to hear that the carer wouldn't carry on due to resource implications for social care. Others understood that this might be a hard question for a professional to ask.

Support the mental and physical health needs of carers

A common feature of the workshops was that carers said that they had usually been asked in general terms “how are you doing?” but that this was often perceived as a passing comment requiring a quick “I'm fine” answer. Carers commented that they were unlikely to explain the actual mental and physical pressure they were feeling when the question was asked in such a brief and

general way, especially as many felt guilty if they were struggling to cope emotionally or physically.

Involve carers in making decisions and choices at all levels

Almost all of the carers who had received a carers assessment said that they were left with no information about how decisions following the assessment were to be made and by whom. Some said that they had been told that decisions would go to a “panel” but none were given any chance to see what was being submitted to the panel, find out who was on the panel or any written information about how decisions made by the panel were reached. Carers therefore experienced a sense of helplessness and disengagement from the process.

Provide support to carers in a way which meets their own individual needs

A significant proportion of carers who had received a carers assessment felt that this had happened in a way that did not meet their needs because it had taken place at a time that took no account of the other pressures on them at that time of day – for example one participant said that the professional had come to the house for an appointment due to be at 2pm but had been 45 minutes late and therefore within 15 minutes she was expecting the person she cares for to be coming home from a day centre. As a result she was no longer be able to talk freely or to focus on the conversation. However, she said that she was not offered an apology for being late, asked whether it was still convenient or offered an alternative time.

Recognise and support carers’ own needs and aspirations

A carer who cares for her brother with learning disabilities was able to return to work ultimately as a result of a carers assessment. However she explained that the first time she tried to raise the fact at her carers assessment that she wanted this option it was not considered and she was told that she could not get any extra help. It was only after she had done extensive research herself and sought the support of other carers in similar situations she realised that her desire to work should be taken into account within the assessment and she felt that this had not been the case. The carer felt that she had to employ considerable assertiveness in order to achieve her aspiration to return to work and that the fact that this had not been considered in her original carers assessment had caused her significant strain and left her feeling depressed and almost at the point of wanting to give up on her aspirations.

Identify and support young carers

Only 3 of the carers involved in the consultation had children who may have been identified as young carers. In one case they were identified and supported by the local carers centre and in another the parent feels they do not take on any caring role or have an impact from the parent's caring role. However, in a third case the carer commented that no professional had ever asked her about the needs of her child when they had seen her or the person with care needs. One carer commented that when the person with care needs is someone with a mental health problem, they felt it might be even less likely for a young person to be recognised as a carer as the care may be more about emotional support than physical care.

Support carers when the caring role ends

One carer had been caring for both her parents before her father died and she now cares for her mother. Although she had informed social care about her father's death she continued to receive communication on several occasions from them about her father as the fact of her father's death did not appear to have been logged centrally so that everyone who needed to know did not. Although this was sorted out after a number of weeks the carer found this quite distressing.

Skills implications

- Relating to Skills for Care Common Core Principles for Working with Carers

Make no assumptions about carers' capacity and willingness to care

Unless expressly told by a carer that they want to carry on caring and are able to do so a professional would have to specifically ask about this if they were not to make an assumption. This appears to be a gap in current practice in the experience of the carers who took part in the consultations. This may be because professionals are aware of the sensitivity attached to the question and the guilt the majority of carers would feel to say that they couldn't or wouldn't carry on. Therefore there may be a need to support professionals to gain the skills to ask this difficult question in a sensitive and clear manner.

Support the mental and physical health needs of carers

Among the sample of those participating, very few carers felt they had a chance to express their mental and physical health concerns. The skills gaps identified by those carers were:

- Delivering the carers assessment in a focused and unhurried way

- Creating an environment where carers feel comfortable to talk – this would involve being clear communication about why the professional is asking about these things, reassurance that the carer is in not being judged, an empathetic manner and encouraging verbal and body language signals to allow the carer to talk freely.
- Conducting the assessment in a way that feels more like a structured discussion than a form-filling exercise
- Understanding that carers may feel guilty, embarrassed or vulnerable to discuss these issues

Involve carers in making decisions and choices at all levels

Some of the carers who care for someone with a mental health problem cited the practices of “Triangle of Care”¹ as being extremely helpful in empowering, respecting and valuing carers and felt that learning from this could be extended to all carers. In particular they mentioned the following workforce development skills:

- Explicitly working with the carer as an expert in the needs of the person they are caring for
- Deliberately making sure that carers receive the opportunity of talking on a one to one basis with professionals at the earliest opportunity
- Providing clear written information to carers to explain what is happening at different steps in the caring journey
- Involving carers as trainers for staff

Carers also felt that they were only able to make decisions when they were fully informed about what choices were available and therefore that staff needed to maintain a comprehensive and up to date knowledge of local services, including those available outside statutory services in the community. In particular this means that staff need to skills to research and understand what services are available and then be able to apply this knowledge creatively when considering different families’ situations.

Decisions and choices are also enabled when professionals give clear communication in advance about the purpose of a carers assessment and allow the carer thinking time before the meeting to consider the sort of things that will be discussed. This then needs to be followed up with clear communication about how and when decisions are to be made after the assessment and how the carer can be involved in that process.

Provide support to carers in a way which meets their own individual needs

The feedback on this area largely relates to the following:

¹– National Mental Health Development Unit and The Princess Royal Trust for Carers (2010)The Triangle of Care – Carers Included – A guide to best practice in acute mental health care , London: NMH DU and PRTC <http://static.carers.org/files/caretriangle-web-5250.pdf>

- Organising timings of carers assessments and other meetings with consideration given to the carer's restrictions and pressures
- Showing respect for the carer's time by attending appointments on time and where possible not cancelling appointments at the last minute as carers may have made complex arrangements in order to make sure they are available

This feedback suggests that organisational skills coupled with developing an understanding of and empathy for carers' situation could be addressed.

There was also a suggestion echoed by a number of carers that staff would benefit from skills in helping carers to express themselves using different mediums – for example through keeping a journal about their feelings or writing down what they are doing each day as well as by encouraging people to be able to speak openly.

A number of carers wanted staff to develop skills around cultural awareness so that they were more able to understand the individual circumstances of each person. For example one carer talked about the stigma she faces in her community if she asks for or accepts any help from outside the family.

Recognise and support carers' own needs and aspirations

Generally carers involved in the consultation had a strong sense of their caring role being their primary responsibility and their personal needs and aspirations being very much secondary. The skills that professionals will need to develop to address this include:

- Basic counselling skills such as a solution-focused approach and ability to draw out issues that are not presenting as most pressing for the carer, to help carers to consider their own needs and not just those of the person with care needs
- Ability to apply knowledge of local services available to help carers access social, educational and work based opportunities specific to their individual needs

Identify and support young carers

This is a specific area that has not been a significant feature of this research and where additional work could be done. However, many studies have shown that identification of young carers is important at the earliest opportunity to achieve the best outcomes for young carers and their families² and therefore all professionals should be aware of the fact that children and young people in families where they are undertaking a carers assessment may be young carers and should know about services available to support them.

² Becker, S., Dearden, C. and Aldridge, J. (2000) Young carers in the UK: research, policy and practice, *Research, Policy and Planning*, Vol. 8, no. 2, pp. 13-22.

Support carers when the caring role ends

As this research has primarily been with those who are currently caring and is centred around carers assessments this is not an area on which this report focuses. However, the impact of bereavement for a carer may have many aspects that are not present for other bereavements, in terms of loss of role, identity and purpose, and it is important that staff understand the depth of impact a caring role and relationship has on those who care.

Telephone interviews across the Carers Trust network

The researcher conducted telephone interviews with professionals working in 8 areas identified by Regional Development Managers in the Carers Trust as employing good practice around carers assessments. Those spoken to are identified in Appendix 3.

Those taking part highlighted the following skills, knowledge and practices as important in conducting effective carers assessments:

Skills

- Distinguishing the extent of the impact of the caring role on the carer rather than just how much caring they are doing. Understanding that it is highly likely that a carer will understate the impact caring is having on them and so being able to draw out a true picture.
- Thinking clearly and broadly around a problem and not just seeing the immediate presenting issue.
- Slow to make judgements and assume anything – rather focusing on the individual carer's situation and experience.
- Good networking and self-driven learning skills so that a comprehensive knowledge of local services and how they fit together is maintained.
- Application of knowledge about services to different carers' circumstances
- Ability to draw up a clear and comprehensive action plan that draws together the agreed actions from the assessment.
- Good observational skills to read body language and to pick up how carers are responding and to see the situation at home.
- Identifying any safeguarding concerns
- Ability to encourage and empower carers to feel able to speak up for themselves and recognise and use their skills and strengths.
- Building a quick rapport, perhaps by identifying a common interest – eg the garden, pet etc.
- Carrying out assessment in a friendly, warm and conversational way that avoids looking like the process is just about filling in a form.
- Refocusing conversations to keep them on track if they start to drift or focus on the cared-for but without losing a conversational approach.
- Teasing out and distinguishing the most important points being raised by the carer from the background information.
- Taking an approach that puts the carer in control and explicitly treating them as the expert in their own situation.
- Making good eye contact and using open body language that demonstrates empathy and encourages the carer to talk honestly and helps carers feel valued and listened-to.

- Asking open questions and giving carers time to think through and explain their answers
- Good literacy levels and ability to express complex situations well on paper
- Recognising that the time spent and approach taken with the carer can itself be a valuable experience for the carer as much as the more concrete outcomes of the assessment.
- Clarity in explaining what can and will be done and dedication to follow that through in a timely fashion. Never promising something that cannot happen.
- Leaving the carer feeling encouraged and positive about the experience and seeing a point to having had the assessment, even if it just means that someone knows about them and they know where to go if things worsen.
- Don't use jargon - use basic and non-technical words.

Knowledge

- A comprehensive and up to date knowledge of local, national and online services available, including specialist carers services, those related to specific conditions and universal services.
- A detailed understanding of the breadth of needs of carers and of the skills and expertise that those who have been caring have gained.
- A good working knowledge of a broad range of conditions and the sort of demands that a condition might place on a carer.
- A health or social care background was valued by most organisations

Practices

- Close collaboration between statutory and voluntary services to both identify carers who are not otherwise accessing support and carry out a smooth carers assessment process. In some cases local carers centres share access to local authority data systems so that carers are quickly, easily and seamlessly referred between services. In Devon, NHS Devon, the County Council and voluntary organisations have worked together to create a new carers assessment that is more holistic and includes a health check.
- A menu of available services that can be offered to carers very quickly following assessment. Examples given included training, social activities, emergency cards and counselling.
- Start assessments from the point of not assuming that a carer wants to continue caring and ask specifically and sensitively about this.
- Proactive review by contacting carers, if they do not have on-going contact, after a period of time.
- Emphasis on face to face contact and allowing enough time to complete a thorough assessment – in general this was estimated to take between 1 and 2 hours.
- Concentrating on carer-focussed outcomes and personal goals.

The following list shows the range of training and support that is offered to staff (and in some cases, volunteers) who are undertaking carers assessments –

- General induction training as given to all staff
- Practical training in computer skills, recording methods etc.
- Specialist courses about conditions – e.g. dementia, mental health
- Adult Social Care provide level 1 and 2 carers support training (Cumbria CC)
- Safeguarding training
- Counselling on the telephone
- Facilitated learning as a team to help standardise processes and ensure that all pool good practice from others
- Weekly team meetings to peer-review assessments and referrals
- In-house staff training package on assessment
- Staff are expected to spend a lot of time shadowing experienced workers before doing assessments themselves
- Carer awareness training – often provided by local carers charities for statutory staff and involving carers
- Basic counselling training
- Staff spending time at carer support groups to listen and learn
- Voluntary sector staff attending local authority induction training and voluntary sector teach a session on carer awareness as part of that induction.

APPENDIX 1

Demographics of carers taking part in workshops

NUMBER OF PEOPLE CARED FOR

18 carers were caring for 1 person

6 carers were caring for 2 people

1 carer was caring for 4 people

GENDER

21 carers were female

4 carers were male

PEOPLE THEY WERE CARING FOR

8 people with learning disabilities

5 people with dementia

3 frail older people

6 people with physical disabilities

7 people with mental ill health

1 person with dual diagnosis mental ill health and drug and alcohol problems

1 person with sensory impairment

2 people with sensory impairment and learning disabilities

1 person with complex and multiple disabilities

CARERS ETHNICITY

15 White British

4 White Other

2 Black Caribbean

2 Asian

1 Black African

1 Mixed White and Black Caribbean

CARERS AGE

80+ - 3

65-80 – 6

50-65 – 6

40-50 – 7

30-40- 3

12 carers knew that they had received a carers assessment, 5 carers knew they had not.

8 carers were unsure whether they had had a carers assessment.

BAD

EXPOSED:
BROKEN
PLEDGE!

Run away train



Over the red line



WHEN GET
not ready
to quit - NOTHING

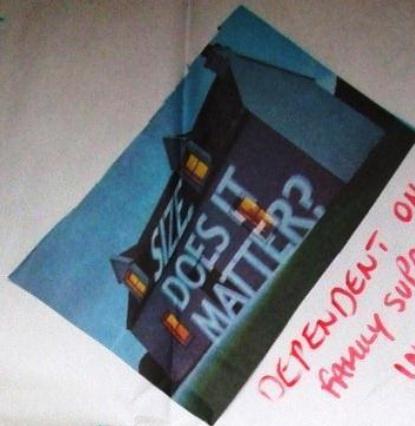
Some get it
Others don't

no follow
up to do
what said
would do.

INEVITABLE

Loss of savings

Everyone
remembers
their first time



DEPENDENT ON INCOME!
FAMILY SUPPORT!
INCOME FROM WORK!

BAD

Don't hold your breath



Not
responsive
to changing
circumstances
as reassess
to needs
change things

Students sit two English exams to help schools boost league rankings

Immigration laws deter gentile students

BBC's full of overpaid pensioners

Just collecting information

UK teens are not clean cut, they're absolutely filthy

Plan fears

One size fits all

Appendix 3

Telephone interview contacts

Carers of Barking and Dagenham - London
The Carers Centre, Bath and North East Somerset
NHS Devon
Furness Carers – Cumbria
Sefton Carers Centre – Merseyside
South Lakeland Carers Association – Cumbria
Swindon Carers Centre – Wiltshire
Carers Support Wiltshire