



In or Out?

Facilitating the voice of disabled people and carers in the design of new eligibility systems proposed under the Care Bill: Feedback from carers and social care users on the draft eligibility criteria

Acknowledgements

We would like to thank all the disabled people and carers who have fed their experiences into this report through the survey, interviews and focus groups.

Thanks to Jose Luis Fernandez at the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE), Helen Undy at Mind and Chloe Wright at Carers UK for their insight and comments in the design of the online survey. Thanks also to Sarah Lambert at the National Autistic Society and Bella Travis at Mencap for facilitating the focus groups that have provided such valuable insight into this report.

Special thanks to Caroline Hawkings, Elliot Dunster and Sarah Bulloch for their insight, comments and analysis during the writing of this report.

And finally, thanks to all the voluntary sector organisations who helped to disseminate the survey through their networks and for helping to recruit social care users to take part in telephone and face-to-face interviews.

Report author: Richard Brady

Copyright Scope, January 2014

Published by Scope, 6 Market Road, London, N7 9PW

This publication is available in alternative formats on request.

Contents

Introduction	4
Key findings	5
Methodology	6
Prominent themes	8
The importance of well-being	8
Definitions of basic personal care and basic household activities	9
The importance of social and communication needs	13
Mobility	16
Understanding ‘significant risk’	17
Fluctuating need	19
Prevention	21
Assessment	22
Carers	24
Understanding the regulations	26
Conclusion	27
Appendix 1: demographics of respondents	28
Appendix 2: The Draft Care and Support (Eligibility Criteria) Regulations	31

Introduction

Through the Department of Health Voluntary Sector Partnership Programme, Scope led research to facilitate the voice of carers and people in receipt of social care on the proposed changes to the eligibility criteria in the Care Bill. (1) The findings of the research are to inform the development of the regulations. The research was carried out between 23 October 2013 and 20 December 2013. This was a collaborative project involving carers and people using services, diverse voluntary sector partners and members of the Department of Health National Task and Finish Group on Eligibility and Assessment. We are grateful to everyone who has contributed their views and advice.

This report outlines the prominent themes and key findings from the research.

1 In the Voluntary Sector Strategic Partnership programme, Scope is a member of the Disability Partnership with Mencap, Sense and the National Autistic Society. The draft eligibility criteria were published by the Department of Health in June 2013.

Key findings

- High quality social care is vital for the well-being of disabled adults of all ages with care needs. Explicit references to well-being in the regulations are essential in reflecting the importance of well-being in the Care Bill.
- More clarity is needed on what is meant by 'significant risk', such as through illustrative examples in statutory guidance and training materials for assessors. Lack of additional clarity regarding the meaning of significant risk is highly likely to result in different interpretations being used across the country, increasing the disparity of provision.
- Definitions of personal care and household activities are broadly accurate, however key activities which impact on an adult's mental well-being, such as communication and social interaction, are missing.
- Mobility around the home is not accurately reflected in the regulations and should be made clearer.
- Regulations should make reference to completing a task reliably, safely and consistently. This should also be taken into account in assessments.
- Explicit reference to fluctuating needs in the regulations is positive. However, the language used is too vague – clear guidance for assessors is required.
- The eligibility criteria need to consider how they can support the policy intention to intervene earlier, in order to prevent, reduce or delay needs from developing.
- Social care user feedback on their experience of the assessment process is generally good. However local authorities need to provide better information about sources of alternative support when a person's needs are deemed ineligible.
- There is widespread concern about how the regulations will be interpreted, highlighting the need for clear guidance and training for assessors.
- The need for specialist training for assessors should be taken into consideration when assessments are to be conducted with people with complex conditions or requiring specialist support.
- Feedback on carers section is inconclusive – further research is required, including with child carers.

Methodology

Method: Mixed method study: online survey, nine interviews, two focus groups. A mixed method study was chosen in order to make the research as inclusive and the sample as representative as possible. Not all people interested in participating were able to access an online survey, therefore nine interviews and two focus groups were conducted in order to give those who were not able to access the survey an opportunity to provide feedback. Additionally, participants were offered the possibility of answering the survey on the phone or in a paper copy. All participants in the research were recruited through networks outside of Scope in order to prevent any researcher bias. Altogether we engaged with **423 disabled people and carers**.

All names used in this report have been changed in order to protect the identity of participants.

Study design:

Online Survey hosted by an independent research agency, Opinium.

Total respondents: 392.

- 229 people in receipt of social care and 163 informal (unpaid) carers. Carers were only consulted as part of the online survey.
- Survey participants were selected using open and closed samples. Closed sample respondents were identified using the research agency's research panel. Open sample respondents were contacted through Voluntary Sector partner and other networks. A brief demographic breakdown of the sample can be found in the Appendix.
- Descriptive analyses of the survey data were conducted by Scope through the use of SPSS and Microsoft Excel.
- Results of the survey were presented to the Department of Health, where opportunity was given to the Department to advise on further analysis.

Eight telephone interviews and one face-to-face interview with disabled people.

- Four people with communication difficulties (dual sensory loss)
- Two people with mental health problems
- Three people with mobility issues (including one respondent with a progressive condition)
- Interview participants were sampled through Voluntary Sector partner networks. 15 partner organisations were contacted to recruit participants for telephone and face to face interviews. A total of **nine** interviews were conducted by the author. Each interview was recorded, transcribed, and analysed using thematic analysis.

Two focus groups

- One run with National Autistic Society with a mix of 10 people on the autistic spectrum and carers
- One run with Mencap with 12 people with a learning disability

Focus Group participants were recruited and hosted by the National Autistic Society and Mencap (Disability sector partners). Key themes were drawn out and incorporated into general qualitative insights around care user's experiences.

Consultative processes:

Online survey: questions were designed in collaboration with Voluntary Sector partners and Mind and Carer's UK to ensure accessibility. A leading academic in the field of social care was also consulted during the design process. The Department of Health was consulted at different stages in the design process and was sent a final version of the survey for information.

Interviews: Voluntary sector partners were consulted for the recruitment of all interviews to ensure opportunity for less represented groups to be included in the research.

Focus Groups: Disability Sector partners, National Autistic Society and Mencap were selected to host focus groups in order to engage with groups that had not yet been consulted within the research. Topic guide and presentations were designed in collaboration with the author.

Prominent themes

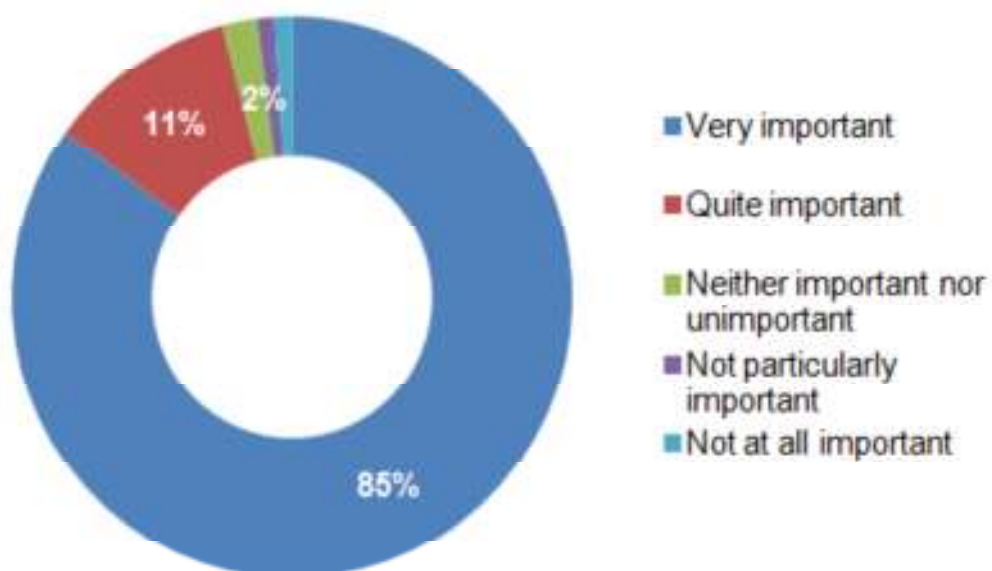
The importance of well-being

Well-being is at the heart of the Government’s social care reforms. The first clause of the Care Bill – the ‘well-being principle’ places a clear emphasis on creating a care system that does not simply focus on ‘feeding and cleaning’, but one that promotes independence and a fulfilling life in the community.

The draft eligibility regulations must therefore seek to reflect the contents of the ‘well-being principle’. The evidence gathered underlines how critical the regulations will be, both to ensuring that this principle is realised in the care system and that those who need care, get it.

It is clear that for those currently eligible, care and support is vital to their well-being. Of the 229 social care users who responded to the survey, 96% said that the social care and support they receive is important to their well-being.

Figure one. How important is receiving social care to your well-being?



Social care is crucial to the well-being of individuals, but when this care does not cover things such as social interaction and communication this fails their well-being. Respondents also identified well-being as being able to maintain a healthy mental state of mind, as distinct from physical well-being and safety.

“Well-being is having a connection with... talking with and building up a relationship with other people. If you’re disabled and you’re always on your own... meeting with other people in the community to build up relationships, a feeling of belonging, that’s all part of your well-being.”

Mark, 48

Key findings

High quality social care is vital to the well-being of people with care needs and explicit references to well-being in the regulations are essential in reflecting the importance of well-being in the Care Bill.

Definitions of basic personal care and basic household activities

The draft eligibility criteria contain definitions of 'basic personal care' and 'basic household activities':

'Basic personal care activities' means essential personal care tasks that a person carries out as part of normal daily life including eating and drinking, maintaining personal hygiene, toileting, getting dressed, and taking medication.

'Basic household activities' means essential household tasks that a person carries out as part of normal daily life including preparing meals, shopping, cleaning and laundry, and managing household finances.

Respondents were asked if they felt that these definitions accurately described what they understand as basic personal care, and basic household activities. From the responses gathered, it can be determined that the definitions are in the main, accurate in providing for **basic** needs.

As one interviewee explains:

"Yes, if you're solely looking at the care. It's a bit like Maslow's hierarchy [of needs], you know, survival."

Mark, 48

In the survey, respondents were asked if they felt that there are any 'activities' missing from the definitions of 'basic personal care' and 'basic household activities'.

Basic personal care activities

Two in three (69%) of survey respondents felt that the description of personal care covered all of the aspects of what they understand as being 'basic personal care' activities.

Of the survey respondents who gave recommendations for extra activities to be included within the definition, three out of four (75%) felt that these should relate to their communication and social needs. Fulfilling basic communication and social needs were seen as fundamental to well-being:

"Having some-one to communicate with, talking to, and some-one who will listen and understand what is needed. Care is not just about washing and shopping, other activities need addressing".

Female survey respondent, 82

“More social communications to prevent mental illness”.

Male survey respondent, 41

“Conversation and feeling like a human being, not just someone on a timetable”.

Female survey respondent, 54

Interviewees and focus group participants were also asked to identify missing activities from the definitions. All of the respondents interviewed were positive in their feedback on the definition of basic personal care activities. Out of the nine people interviewed, none of the respondents gave recommendations for additional activities, all considering the description of basic personal care activities to be inclusive of their basic personal care needs.

“I think they reflect the essential happening around personal care needs. Yes, I would be perfectly happy with those”.

Edward, 49

“Well, to be fair I think that that covers personal care because personal care is care of one’s person”.

Frances, 50

One interviewee made particular reference to the language used in the description of basic personal care.

“Well, personal care and I suppose what I liked about it actually was that for once they put personal hygiene instead of toileting because as woman, you might need certain support on checking things”.

Lucy, 41

Basic household activities

The description of basic household activities provided in the regulations was well received by the majority of survey, interview and focus group participants. Only 15% of survey respondents offered recommendations for extra household activities to be included in the description.

Over half (59%) of those who did recommend additional activities made clear that additional activities should impact upon their communication and social needs.

“To be able to access social activities and interact with others”.

Female survey respondent, 63

“Help with acquiring and maintaining friendships and social activities”.

Female survey respondent, 34

Where respondents did make recommendations for specific activities to be included, the most common responses related to maintaining one's property or an outdoor space, such as a garden.

These responses were mirrored by interviewees and focus group participants.

“I would say decorating and keeping up a home to certain standards in the home. That to me, every household activity that everybody else takes for granted, is a massive issue for people who would be on the eligibility criteria. You know, just keeping your home tidy, painting, decorating, moving furniture...”

Mark, 48

Not all of the activities mentioned above, such as painting and decorating may strictly be considered as 'basic' household activities. However, the evidence indicates the importance of maintaining one's home to a decent standard and clearly a person's home environment impacts on their well-being, health and safety. For example, maintaining a tidy home has safety implications for people who are sight impaired and therefore is essential.

“I guess what the social care criteria will not take into account is people's wider needs as regard to independent living, which it should do in my opinion”.

Edward, 49

“I know someone who needs his garden maintained. It's really important to this particular individual that I know. That sustains him... he would say and a few others [social care users] that that's a basic household activity”.

Mark, 48

As Mark explains, completing what he describes as a basic household activity can have a substantial impact on a person's well-being. It is evident that activities included within the regulations go some way to ensure the **physical** well-being of an adult, however the volume of responses across all data sources strongly suggest that there are still activities relating to communication and social interaction missing from the regulations that impact on an adult's mental well-being.

Key findings

There was general consensus that definitions of personal care and household activities are broadly accurate.

However, the evidence clearly identifies a number of areas missing from the regulations. These are related to an adult's mental well-being and more specifically about communication and social interaction. Social care is crucial to the well-being of individuals who need care, but when care does not cover things such as communication and social interaction, this fails their well-being.

The reoccurring themes around 'home maintenance' suggests a significant level of unmet need in the system.

Interpreting basic personal care and basic household activities

Although the definitions of basic personal care and basic household activities were also well received in both focus groups, there was concern about how these definitions might be interpreted during an assessment. Participants feared that because a person may be able to complete all basic personal care and basic household activities, they would be considered ineligible, even though they may not be able to do so "reliably, safely and consistently".

This is illustrated in the following extract from a focus group.

Participant one: "...Is unable to carry out one or more basic care activities" ... we should add in "unable to carry out reliably and safely".

Participant two: And consistently.

Participant one: And consistently because that's the point. They could carry it out but are they going to do it "safely and reliably and properly", which a lot of autistic people just won't do.

Facilitator: Then the basic household activities one, so that says, "person is unable to carry out one or more basic household activities and as a consequence, there is a 'significant risk' to any aspect of the adult's wellbeing.

Participant one: Again, "reliably, safely and consistently" needs to be put in.

Participant three: Yeah, because in the sense of cooking, someone with autism might know how to cook one specific meal but we've got a duty to support them to cook different meals so the Government could say well they can cook but they can't necessarily cook something which would...

Facilitator: Be nutritious...

Participant one: Yeah, this is very difficult because in the sense of cooking. “Can you cook?” “Yes, I can make a piece of toast but that’s it, I can’t cook with an oven.” Possibly only with a microwave, so it’s these sorts of things or simple things like using knives. My daughter was always cutting herself, which is why the safety bit has to come in...

Participant one: And I would also say getting appropriately dressed because Asperger’s are notorious for getting hot and cold like we have no idea about. They could go out in the snow in a pair of shorts or a bikini...

Participant two: And three coats in the summer. With a hat on! **[all laughing]**

Participant one: Yes!

Focus group participants in particular were concerned that an adult’s ability to complete basic personal care and basic household activities to a certain degree, would impact on their eligibility for care and support. For example, an adult may be able to feed themselves and prepare certain meals but does not necessarily mean that they are able to maintain a healthy and nutritious diet.

Key findings

Regulations should make reference to completing a task in an appropriate manner. This should also be taken into account in assessments.

The importance of social and communication needs

Key aspects of well-being related to communication and social needs are currently missing. The responses given by participants in all mediums of the research illustrates the importance of these needs being met.

Social needs

Respondents feel that social care and support should enable them to be a part of their local community.

As previously reported, over two thirds of survey respondents who made recommendations for additional basic personal care activities and over half of those who suggested additional basic household activities did so in relation to their communication and social needs. At present, disabled people feel that they are being denied support to maintain these needs.

“My participating in a community is not regarded as a necessity”.

Katherine, 54

“Part of the problem with accessing social activities is that people think, “Well why do you want a social life?” and the answer is that I am a human being”.

Vivien, 72

“You can’t keep us [disabled people] in isolation, you’ve got to join up and see how this is going to aid in independent living. All of those things need to be joined up for this element to work because I just don’t ... most people say, “I just don’t want to just survive”. If that’s what you’re telling me I have a choice of, surviving, where everybody else can flourish, they [non-disabled people] don’t have to think about these choices”.

Mark, 48

One interviewee receives a direct payment for her social care. She said that currently, her ‘social’ needs are not deemed eligible. However, she considers this aspect of her life to be so important that she makes ‘sacrifices’ on other elements of her care package, so that she can access her local community and visit friends.

“I want to be able to visit my old neighbour, who doesn’t have a car anymore, who lives in a village next door. I want to be able to go into the community, visit some museums, some art exhibitions, a café, why not?”

Katherine, 54

There is concern that in its current form, the draft eligibility criteria will not enable disabled people to get the support they need to maintain their well-being. Disabled people feel that at present, the support they receive does not help them to access their local communities and to interact socially. Feeling as though you are part of your local community and being able to socialise with people is central to the well-being of disabled people.

“What we’re talking about is access to social activities and things like that and I don’t think it comes out clearly here. ‘Unable to access necessary facilities or services in the local community’ that means banking to me, that means... you know, shops and things like that and not actually social networking”

Focus group participant

Respondents emphasised that providing care and support in order to maintain a healthy well-being can keep them out of crisis.

“If I’m given the support to do tasks that I find difficult and that take a long time then it means that I can access the community better, I can take part in other activities that are important to me, like social activities and things. So yes, I think people should be able to get support if it means that they can get out and about and do the things that make up a human being”.

Vivien, 72

Communication needs

The ability to communicate is an issue that affects many disabled people. Disabled people believe that this is a basic need and that this need should be included in social care and support. Respondents feel that communication is central to well-being and are concerned that it does not feature in the regulations.

“I know they’ve [The Government] got to be mindful but my concern, we’ve got past the personal tasks, but as I said, there’s nothing in there at all about communication, which is a big concern.”

Lucy, 41

“Communication is something we haven’t mentioned, that is vital because if you have an assessment and that person that’s doing the assessment is not able to communicate with somebody, how can that person explain what they need?”

Edward, 49

Many disabled people, especially those with dual sensory loss, rely on having a communication guide to be able to complete basic household activities such as managing household finances and shopping. Two social care users interviewed do not have communication guides as part of their care and support package and as a result are not able to complete some basic household activities.

“I’m vulnerable being blind and not being able to see, I mean, I fell down when I used to go out on my own so now I don’t go out unless I’ve got a com[munication] guide. Same with shopping. I have to use a com[munication] guide to do the shopping”

(Sam, 65)

“If I need a communication guide or something, I know where to get one. It’s not cheap!”

Graham, 73

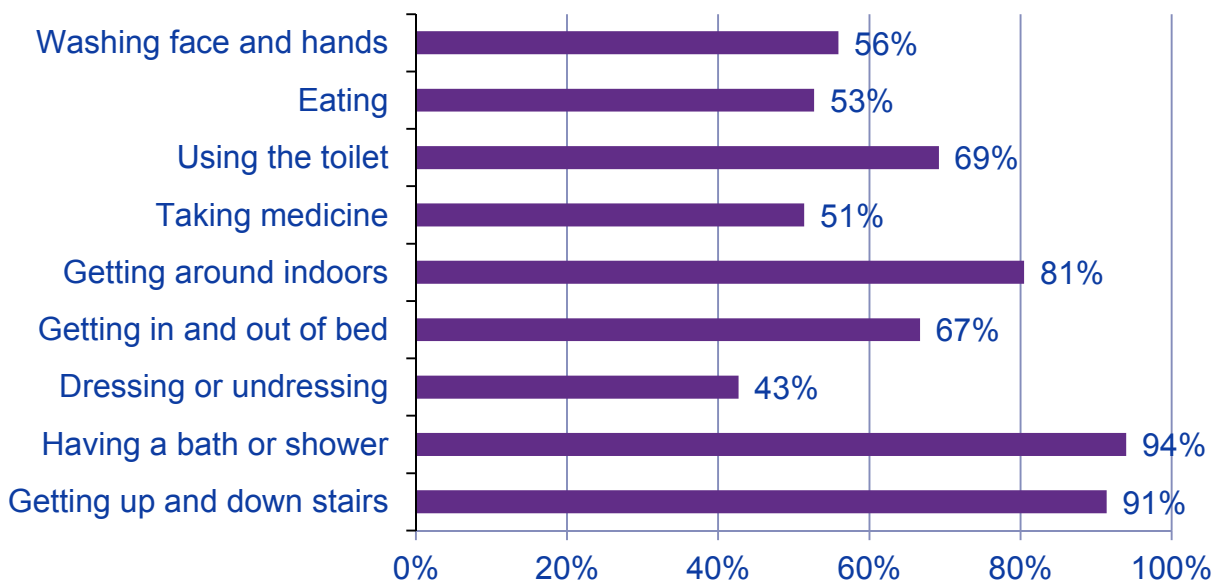
The recurring themes of fulfilling communication and social needs by social care users highlights the level of unmet need in these areas. It is recommended that the Department of Health considers how adequately basic communication and social needs are covered, where these relate to basic personal care and basic household activities.

Mobility

Survey respondents were asked what activities they were able to complete on their own, but with difficulty and which in doing so, endangered the health and safety of themselves or another person.

As can be seen in the table below, the activities that were identified as being the most problematic for survey respondents all follow one common theme: mobility. Whilst using the toilet and having a bath or shower are included within the regulations, getting in and out of bed, getting up and down stairs and getting around indoors are not. These are all included in the standard list of activities of daily living (ADLs). (2) Many of the survey respondents feel that they are unable to complete these tasks without endangering the health and safety of themselves or others.

Figure two. Activities completed on own with difficulty that endanger the health and safety of self or others



2 Activities of Daily Living (ADLs) are defined by the Health and Social Care Information Centre <http://www.hscic.gov.uk/catalogue/PUB09300/HSE2011-Ch5-Social-Care.pdf#page=7>

Key findings

Fulfilling communication and social needs is central to the mental well-being of disabled people and these should be reflected in the regulations.

Mobility around the home – including getting in and out of bed – is not accurately reflected in the regulations and should be made clearer.

Understanding of significant risk

Social care users understood that the phrase ‘significant risk to any aspect of the adult’s wellbeing’ is used in the draft regulations as the measure by which a local authority will assess an individual’s eligibility for care and support.

Furthermore, 52% of the survey respondents said that they understood the meaning of the term ‘significant risk’. As can be seen in the table below, care users understand the term as something very serious, broadly equivalent to the descriptors used in the current FACS criteria to describe someone with ‘critical’ care needs.

Figure three. Defining significant risk

Respondent's definition of 'significant risk'	Equivalence under current FACS = 'Critical'
"Serious health problems and not able to care for themselves."	"Significant health problems have developed or will develop."
"It means that without the support the cared for person would become seriously ill or even die."	"Life is, or will be threatened."
"This means you are a danger to someone else physically or mentally. And maybe a danger to yourself such as Suicide, and so on."	"Serious abuse or neglect has occurred or will occur."
"Terminal, a danger to oneself, for example, cannot carry out basic functions at all or without assistance."	"Inability to carry out vital personal care or domestic routines."
"Significant risk means that the person is a danger to themselves if they are left alone. Such as my partner who would cross the road without looking, not take necessary medication or forget that he had taken it and take more, leave pans unattended or lit gas rings, boil kettles dry and such like."	"Serious abuse or neglect has occurred or will occur."
Avoid suicidal, life threatening issues.	"Life is, or will be threatened."

Interviewees were also asked to provide feedback on what the phrase significant risk means to them. Interviewees see the term 'significant risk' as the gateway to receiving care and support. Respondents expressed a concern with how 'significant risk' might be interpreted as a person's eligibility will be determined by an assessor's interpretation of 'significant risk' to wellbeing.

They outlined the ambiguous nature of the term:

"That actually needs more spelling out because someone's 'significant' is someone else's 'minimum' kind of risk"

Edward, 49

“What does ‘significant’ mean when we’re talking about risk? There is a significant risk to any aspect of the adult’s well-being, the whole of those points, those words that I’ve mentioned, need unpicking.”

Mark, 48

“The trouble with all these words is how do you measure whether something is significant? That can be interpreted by different people differently”.

Lucy, 41

Key findings

Respondents saw this phrase as the key gateway in the regulations to getting care and support.

Care users understood the term ‘significant risk’ as broadly the equivalent to ‘critical’ under the current FACS criteria. For the regulations to be applied consistently across the country at the Government’s intended level of ‘substantial’ under the current FACS criteria, illustrative examples and training materials for assessors must be provided.

More clarity is needed on what is meant by ‘significant risk’. Lack of additional clarity regarding the meaning of significant risk is highly likely to result in different interpretations being used across the country, increasing the disparity of provision.

Fluctuating need

Section two, part (three) of the regulations states:

Where an adult’s needs fluctuate, in determining whether the adult’s needs meet the eligibility criteria, the local authority shall take into account the adult’s circumstances over such period as it considers necessary to establish an accurate indication of the adult’s ongoing level of need.

The recognition of fluctuating needs as a specific section in the regulations is welcomed by social care users and is seen as positive. However respondents voiced concerns as to how a fluctuating need might be interpreted. Three out of four survey respondents who are in receipt of social care services stated that they had a fluctuating need. In addition, nearly half (45%) of all survey respondents in receipt of social care said that their needs vary on a daily basis. People’s needs fluctuate with a range of different conditions, recognising this within the regulations is very important to disabled people.

There are however concerns that the language used is vague and that an adult's level of eligibility will be too reliant on the interpretation of the individual carrying out the assessment.

“I think it is rather ambiguous. They're not committing themselves to anything there; are they? They're not actually saying what they will do; they are saying that when the needs fluctuate, we'll look at it to assess how it fluctuates and over what length and period. What length of time but what are they going [to do], what are they saying? I don't understand how they're going to assess that”.

Frances, 50

“If you don't meet the criteria on the particular day that you're assessed, then you won't get the support”.

Vivien, 72

Many respondents, particularly those with mental health problems feel that a lot of emphasis is placed on how they will be functioning on the day of an assessment and that there is a need for a more holistic approach to assessment.

One respondent commented that the support that she received was stopped after attending a follow up assessment:

“I was dropped early in the year and was told I no longer needed their service because I have been very 'up' the last couple of times they have seen me”.

Frances, 50

Key findings

Explicit reference to fluctuating needs in the regulations is positively received.

The language used is too vague – clearer guidance is needed.

Respondents feel that their eligibility for care and support rests on how they are during an assessment.

Prevention

Providing social care and support to a person with a fluctuating need can help to prevent a condition from getting worse. One interviewee spoke at length about his progressive condition and the difficulties in getting timely support because his condition changes. Edward now receives care and support as his needs are now assessed as being 'Substantial', however, he believes that if he had been given care and support at an earlier stage, this would have prevented his condition from accelerating as quickly as it did.

"In fact, so much so because of the lack... my local authority of London, they are... because they decided not to support me with low level needs at the time, meant my health is in a much worse condition now. I do speak from experience from setting criteria too low that you're in fact, doing some long-term damage to many individuals".

Edward, 49

"I really fear for people with fluctuating conditions like I had when I was younger. I had tried registering [for care and support] at the start when I might have not had the needs that would always present themselves but they would present themselves there in the future".

Edward, 49

Physical conditions that are proven to be progressive, such as muscular dystrophy and MS may not present as having a high level of need during the early stages of a person's life but without the right level of support can accelerate quickly. Edward feels the an assessor's interpretation of a fluctuating need was crucial to whether or not a person would be eligible for care and support and that if needs were not presenting during the time of assessment this would make it more difficult to get support.

"I think they [Local Authorities] will turn around and say, "Well, his needs are fluctuating but he's not needing support as of yet so we might consider this period of fluctuation a bit longer." It would actually give them a way of not providing any support. I'm actually seeing dangers in that".

Edward, 49

"I think by setting the criteria at either substantial or critical is going to exclude an awful lot of people with neuro-muscular conditions or conditions that worsen. Maybe conditions that people acquire through accident, again, there's many cases where conditions will actually worsen without a social care package in place".

Edward, 49

As Edward's experience illustrates, setting a high threshold for support is at odds with the aim addressing needs at an earlier stage to prevent them from getting worse.

Key findings

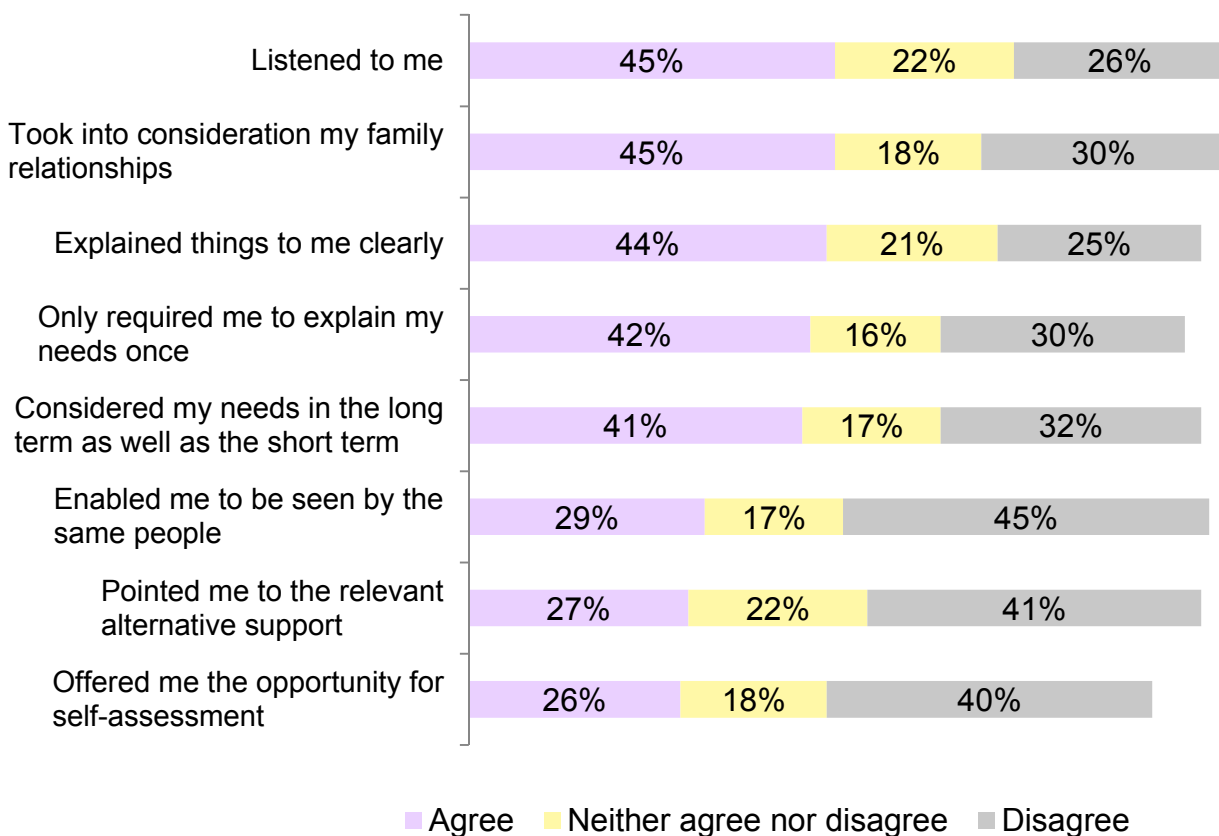
Providing social care and support to someone with a progressive condition at an early stage can help offset the presentation of higher support needs later on in life. The eligibility criteria need to consider how they can support the policy intention to intervene earlier, in order to prevent, reduce or delay needs from developing.

Assessment

We used the research as an opportunity to ask for topline feedback on assessments.

Survey respondents were asked how much they agreed with the statements below when reflecting on the last assessment that they had. As the table below shows, social care users were generally satisfied with many parts of the assessment process. However, the main areas in which they disagreed were with being able to be seen by the same person (45%), being pointed to the relevant alternative support (41%) and offering the opportunity for self-assessment (40%).

Figure four. Survey respondents' experiences of assessment. Survey respondents were asked if the person carrying out their most recent assessment did the following:



Local Authorities will be under a duty to provide information on relevant alternative support, irrespective of a person's eligibility and it is important that this is addressed.

The interpretation of the regulations during an assessment was of most concern to interviewees and focus group participants. Respondents felt that if an assessor did not have specialist training in a specific condition they would not be able to accurately interpret the regulations.

One focus group participant felt particularly strongly about this:

“I think this is fundamental to everything. These criteria are going to be used by assessors. Unless the assessors are trained thoroughly in Asperger's and autism, they will not understand how to relate the condition to these things. So training should be mandatory, it should be urgent, it should be done by every single area in the country because those are the people that are going to decide the future of your children's lives and consequently, our lives. So I think Asperger's and autistic people should refuse to see anybody, any assessor who cannot guarantee they've been trained in autism. I wouldn't let my daughter go unless they knew about autism. I've seen what happens when they don't”.

Focus Group Participant

In 2009, statutory guidance on assessment for deafblind people was issued. Within this guidance it states:

When an assessment is required or requested, it is carried out by a specifically trained person / team, equipped to assess the needs of a deafblind person – in particular to assess need for one-to-one human contact, assistive technology and rehabilitation.

Social care for deafblind children and adults statutory guidance 2009

The importance of specialist training to carry out assessments has already been recognised with deafblind people and it was felt that every adult should be assessed by a person with the appropriate skills and experience.

One interviewee feels that there is too much pressure on assessors to manage care budgets and that in doing so has a substantial impact when carrying out an assessment.

“How can you have the same people assessing you who are the gatekeepers of the care? That is an issue of transparency, the trust in the system, so basically the same people are telling you that massive cuts are going to happen. So you know, you've already created a defence, so you're not really going to reflect true transparency and accountability when you're already on the back foot knowing you're cash-strapped because all councils have said it and this can be seen as a cost-cutting exercise”

Mark, 48

Key findings

Social care user feedback on their experience of current assessments is generally good. However local authorities need to provide better information about sources of alternative support when a person's needs are deemed ineligible.

Every adult should be assessed by a person with the appropriate skills and experience. The need for specialist training for assessors should be taken into consideration when assessments are to be conducted with people with complex conditions requiring specialist support.

Carers

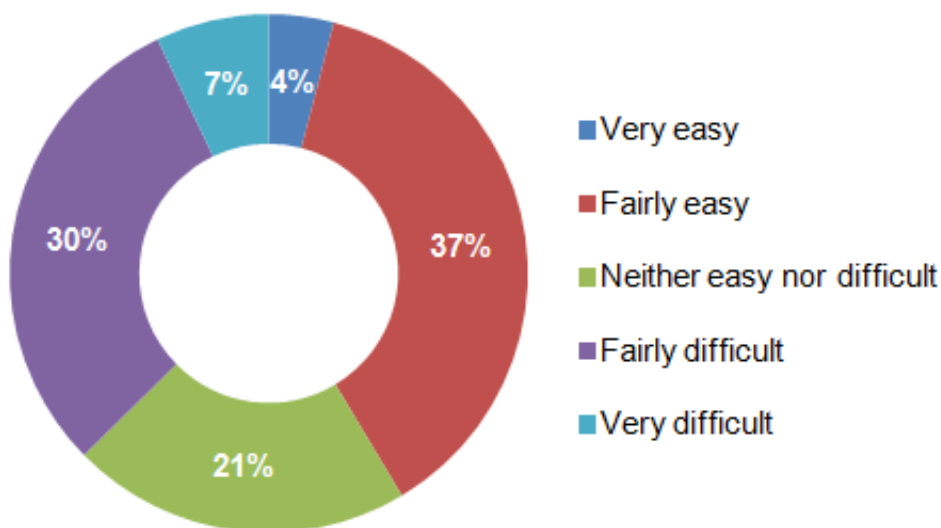
The introduction of the eligibility criteria for carers is welcomed by both carers and social care users alike. Family members often take on the role of an informal carer when a relative is in need of care and support. Many informal carers have other responsibilities such as working full-time jobs or taking care of children whilst providing care and support to a disabled relative. Social care users that we spoke to welcome the introduction of an eligibility criteria for carers as currently, many feel that the role of informal carer compromises a disabled person's eligibility for support.

“Because I have my wife, if someone's assessing you, they will say, “You do not need that [care and support] because somebody else can do it for you. It's blurry, that relationship. It's great if you're on your own and you're independent and someone comes in and does that but how much of my personal care should be done by my wife or my daughter?”

Mark, 48

As this is the first time that eligibility criteria will be implemented for carers, carers were asked how easy they found the draft regulations to understand. Having been shown the draft regulations, 41% found the draft regulations easy to understand, 37% found them hard to understand.

Figure five. Carers' understanding of the draft regulations.



After reading the draft regulations, how easy or difficult are they to understand?

Survey respondents were asked if they felt that they would be eligible for care and support if the draft eligibility criteria were to be implemented in its current format. Around half (44%) were unsure whether they would be eligible for care and support.

Respondents were also uncertain about where the threshold for support was. Responses were mixed, with 27% stating that they felt the threshold for support was too high, 21% saying it was too low, 32% saying that they felt it was just right with the remaining 20% saying that they didn't know.

“I just think it's good that... well, I hope they do recognise my husband... his needs are covered and the fact that if people can't remain in employment or people like my husband, where it says his mental and physical health could deteriorate, and it also talks about him having recreational activities for himself type thing, I think it covered quite a few circumstances quite well. You know, [the situation] that informal carers can find themselves in, and obviously the isolation that they face as well. I don't know if the word isolation is used anywhere in the regulations but maybe they're isolated”.

Lucy, 41

Key findings

It is recommended that further research be conducted in order to gain more detailed feedback from informal carers, including young carers as the limited findings presented in this report are inconclusive.

Understanding the regulations

Survey respondents were asked how easy or difficult they found the regulations to understand in their current format. Of those who had difficulty understanding the draft regulations, 57% agreed that if they were written in plain English it would help make sense of them. Further improvements to help understand the regulations are as follows:

- Have somebody explain them (44%)
- Easy read version (40%)
- Additional guidance document to help explain (29%)
- Images and illustrations (28%)

“For me it would be better if there would be an easy-read version of this... You’ve got a vast array of people who will be knocking on the door for assistance and who do not know how to navigate or understand the jargon... Whatever guidance it comes along with has got to be a story that is understand[able] to the end person who is trying to navigate this, and that’s what’s missing... It’s still quite wordy, you want something punchy, that tells a story”.

Mark, 48

“It [the draft criteria] is better than it has ever been. It had been very offputting and in fact it made you more ill than you were, just by reading it! [FACS criteria]”

Frances, 50

Key findings

In order to engage with disabled people effectively, it is recommended that the Department of Health produce an easy read version of the regulations when the regulations go to public consultation.

Conclusion

Feedback from people in receipt of social care and carers suggests that there are many positive aspects to the draft eligibility criteria.

- There was strong consensus that care and support is essential to well-being and respondents welcomed explicit references to well-being.
- The research revealed high levels of fluctuating need and so it is particularly welcome that this is specifically recognised.
- Respondents felt that on the whole definitions of 'basic personal care' and 'basic household activities' are broadly accurate.

Whilst the descriptions of basic personal care and basic household activities were seen to be generally correct, respondents felt that activities relating to communication, social interaction and mobility are central to maintaining well-being and independence and are not sufficiently reflected. These areas should be more explicit in the final regulations.

Despite consensus that definitions provided in the regulations are broadly accurate, care users and their carers are extremely worried about how the criteria will be interpreted by assessors. Crucial to this is the interpretation of the phrase 'significant risk'. Care users understand the phrase 'significant risk' to be the gateway for eligibility for care, and they understand this phrase equates to the equivalent to 'Critical' under the current FACS criteria.

For the Government to meet their policy intention for the regulations to be broadly the equivalent of 'Substantial' under FACS (3) guidance published alongside the regulations must clarify this definition. This will be crucial in ensuring the regulations are enacted consistently across the country, eliminating the 'post code lottery' for care as intended.

We realise the challenges involved in this work. Scope and other organisations, together with carers and people using services welcome ongoing involvement and will continue to engage with the Department of Health as regulations and guidance develop.

³ Draft national minimum eligibility threshold for adult care and support: A discussion document
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/209595/National_Eligibility_Criteria_-_discussion_document.pdf#page=6

Appendix 1

Social care user demographics: Sample size: 229*

Gender	Number	Percentage
Male	62	27%
Female	167	73%
Age		
18-34	32	14%
35-64	158	69%
65+	39	17%
Region		
North East	14	6%
North West	31	14%
Yorkshire & Humberside	20	9%
East Midlands	20	9%
West Midlands	13	6%
East of England	32	14%
London	17	7%
South East	29	13%
South West	24	10%
Wales	10	4%
Scotland	16	7%
Northern Ireland	3	1%
Employment status		
Working full time (30 or more hours per week)	30	13%
Working part time (8 - 29 hours per week)	18	8%
Working part time (Less than 8 hours a week)	14	6%
Full time student	4	2%
Retired	55	24%
Unemployed	30	13%

Other not working	78	34%
Effect of impairment		
Mobility (moving about)	118	69%
Lifting, carrying or moving objects	104	61%
Manual dexterity (using your hands to carry out everyday tasks)	72	42%
Continence (bladder and bowel control)	61	36%
Communication (speech, hearing or eyesight)	58	34%
Memory or ability to concentrate, learn or understand	87	51%
Recognising when you are in physical danger	56	33%
Your physical co-ordination (such as balance)	91	54%
A fluctuating or long-term health problem or condition (cancer, HIV / AIDS or ME)	44	26%
Other area of life (please specify)	28	16%
None of these	3	2%
Prefer not to say	8	5%

*Column total do not always sum to 229 due to responses to multiple answer questions

Carer demographics: Sample size: 163

Gender	Number	Percentage
Male	36	22%
Female	127	78%
Age		
18-34	25	15%
35-64	112	69%
65+	26	16%
Region		
North East	6	4%
North West	23	14%
Yorkshire & Humberside	18	11%
East Midlands	11	7%

West Midlands	11	7%
East of England	27	17%
London	10	6%
South East	24	15%
South West	17	10%
Wales	4	2%
Scotland	8	5%
Northern Ireland	4	2%
Employment status		
Working full time (30 or more hours per week)	40	25%
Working part time (8 - 29 hours per week)	27	17%
Working part time (Less than 8 hours a week)	7	4%
Full time student	3	2%
Retired	37	23%
Unemployed	17	10%
Other not working	32	20%
Do you consider yourself to be disabled?		
Yes	51	31%
No	101	62%
Not sure	11	7%

Draft Regulations laid before Parliament under section 109(4) of the Care Act 2014, for approval by resolution of each House of Parliament.*

Appendix 2

Draft Statutory Instruments

201x No. 000

Care and Support, England

The Care and Support (Eligibility Criteria) Regulations 201x

*Made - - - - ****

*Coming into force - - ****

The Secretary of State makes the following Regulations in exercise of the powers conferred by sections

13(7) and (8) and 109(6) of the Care Act 201x⁽³⁾.

⁽³⁾ 201x c.xx.

A draft of this instrument has been laid before and approved by a resolution of each House of Parliament in accordance with section 109(4) of that Act.

Citation, commencement and interpretation

1.—(1) These Regulations may be cited as the Care and Support (Eligibility Criteria) Regulations 201x and shall come into force on xx. (2) In these Regulations—

“basic personal care activities” means essential personal care tasks that a person carries out as part of normal daily life including eating and drinking, maintaining personal hygiene, toileting, getting dressed, and taking medication; and

“basic household activities” means essential household tasks that a person carries out as part of normal daily life including preparing meals, shopping, cleaning and laundry, and managing household finances.

Needs which meet the eligibility criteria: adults who need care and support

2. An adult’s needs meet the eligibility criteria if those needs are due to a physical or mental impairment or illness and the effect of such needs is that the adult— (a) is unable to carry out one or more basic personal care activities and as a consequence there is a significant risk to any aspect of the adult’s well-being;

(b) is unable to carry out one or more basic household activities and as a consequence there is a significant risk to any aspect of the adult’s well-being;

(c) is unable to fully carry out any caring responsibilities the adult has for a child;

(d) needs support to maintain family or other personal relationships, and a failure to sustain such relationships has or is likely to have a significant impact on the adult’s well-being;

(e) is unable to access and engage in work, training, education or volunteering and as a consequence there is a significant risk to any aspect of the adult’s well-being; or

(f) is unable to access necessary facilities or services in the local community and as a consequence there is a significant risk to any aspect of the adult’s well-being.

(2) For the purposes of paragraph (1) an adult is to be regarded as being unable to carry out a task if the adult— (a) is unable to complete the task without assistance;

- (b) is able to complete the task without assistance but doing so causes the adult significant pain, distress or anxiety;
 - (c) is able to complete the task without assistance but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or
 - (d) is able to complete the task without assistance but takes significantly longer than would normally be expected.
- (3) Where an adult's needs fluctuate, in determining whether the adult's needs meet the eligibility criteria, the local authority shall take into account the adult's circumstances over such period as it considers necessary to establish an accurate indication of the adult's ongoing level of need.

Needs which meet the eligibility criteria: carers

3. A carer's needs meet the eligibility criteria if the effect of those needs is that any of circumstances specified in regulation 4 apply to the carer, or are expected to apply at an identifiable point in the future.

4.—(1) The circumstances referred to in regulation 3 are as follows: (a) the carer is unable or unwilling to provide some of the necessary care to the adult needing care;

(b) as a consequence of providing care, the carer is unable to carry out some or all basic household activities in the carer's home (whether or not this is also the home of the adult needing care);

(c) as a consequence of providing care, the carer's physical or mental health is, or is at risk of, significantly deteriorating;

(d) as a consequence of providing care the carer is, or is likely to be— (i) unable fully to care for any child for whom the carer is responsible,

(ii) unable fully to provide care to other persons for whom the carer provides care, or

(iii) unable fully to maintain other family or personal relationships;

(e) as a consequence of providing care, the carer is, or is likely to be, unable to obtain or remain in employment, education or training;

(f) as a consequence of providing care, the carer is unable to access necessary facilities or services in the local community; or

(g) as a consequence of providing care, the carer is unable to participate in recreational activities.

(2) For the purposes of paragraph (1) a carer is to be regarded as being unable to provide the necessary care if the carer— (a) is unable to provide the care without assistance;

(b) is able to provide the care without assistance but doing so— (i) causes or is likely to cause either the carer or the adult needing care significant pain, distress or anxiety; or

(ii) endangers or is likely to endanger the health or safety of the carer or the adult needing care.

About Scope

Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here.

We provide support, information and advice to more than a quarter of a million disabled people and their families every year. We raise awareness of the issues that matter.

And with your support, we'll keep driving change across society until this country is great for everyone.

www.scope.org.uk

Scope is a Department of Health Voluntary Sector Strategic Partner, and within this programme Scope is a member of the Disability Partnership with Mencap, Sense and the National Autistic Society.