

# Too Ashamed to Complain: Cuts to Publicly Financed Care and Clients' Waiving of their Right to Appeal

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*This article examines how Dutch citizens with long-term care needs have used existing legal opportunities to respond to cuts in publicly financed care. Unexpectedly, most did not make use of their right to appeal the reduction or elimination of their previous entitlements, even when this led to marked problems in daily life. Thirty interviews with disabled and elderly persons and their care-givers revealed that specific social norms on how to feel about the cuts inhibited the lodging of appeals. Given the new policy's stated intention of preserving care for the most needy, many affected clients felt they had no right to be angry. Despite their (often objectively warranted) grievances, they did not appeal as breaking with the new moral code would trigger feelings of shame – of not being autonomous, of demanding too much when others are worse off, and of appearing ungrateful.*

**Keywords:** Long-term care, cuts to the welfare state, right to appeal, feeling rules, shame.

## Introduction

Democratic welfare states allow citizens to express their dissatisfaction with the quality and allocation of healthcare and social services in numerous ways, including through informal complaints, legal procedures against the authorities (for example, the right to appeal), the exercise of individual 'choice' when consuming services (for example, via cash-for-care) and politically via patients' rights organisations. Nevertheless, dissatisfaction in most cases is not expressed in any of these ways. Mulcahy and Tritter (1998), for example, found that only about one in ten dissatisfied healthcare clients lodge formal complaints.

How can we make sense of something that *people do not do*, in this case not making use of the right to appeal against cuts to publicly financed care and waiving the chance to maintain their previous entitlements? The question of non-take up has been raised more generally within legal studies (for example, Briar, 1966; Sarat, 1990), in poverty research (for example, Kerr, 1983; Van Oorschot, 1991, 1995), in social policy studies (for example, Lens and Vorsanger, 2005; Aronson, 2006; Allsop and Jones, 2007; Gulland, 2011) and in social movement studies, upon which we primarily base our approach. Within social movement studies 'failure to act' has been traced to the lack of resources and skills (Verba

et al., 1995), a lack of political opportunities (Kriesi et al., 1992; McAdam et al., 2001) or, more precisely, lack of support by those in power (Lowndes et al., 2006). Mulcahy and Tritter (1998) suggest that not making use of the right to appeal is mostly couched in negative terms, as a failure on the part of dissatisfied clients or on the part of the complaints system as a whole.

As in many other countries, citizens in the Netherlands are encouraged to mobilise their private networks to arrange for long-term care (LTC) before seeking state support (see Glendinning and Moran, 2009; Newman and Tonkens, 2011). Recent policies summoning such 'active citizenship' posit that public goods, such as the provision of care, are best arranged at the lowest feasible level of organisation, such as the family and community (Jordan, 2010: 11). Against the background of an ageing population and economic crisis, the government deems cutbacks to healthcare both desirable and necessary: necessary because LTC costs have ballooned over the past decades, and desirable because the services-led model is said to have disengaged citizens from informal care-giving and alienated disabled and elderly persons from mainstream society. To contain costs and to encourage citizens to take a greater role in informal care-giving, care under the Dutch Social Support Act (Wet Maatschappelijke Ondersteuning, WMO (Sijtema, 2006)) is no longer a legal right of citizenship (c.f. Cox, 1998). Recent legislation restricts access to LTC to the most severely disabled, or in political rhetoric, to those who 'really need it'. The rhetoric furthermore suggests that there are 'welfare queens' receiving excessive care, at times fraudulently (Gustafson, 2011). Implicitly, the rhetoric also suggests that those who are not 'genuinely disabled' should feel guilty about using publicly financed care.

In Europe, welfare state clients reclassified as ineligible for publicly financed care have several avenues to express disagreement. Alongside the right to an individual re-assessment of their needs, many countries guarantee the right to procedural fairness. Most European welfare states recognise the right to appeal against the authority handling individual assessments (Vabø, 2012: 4). In some countries (for example, the UK), care professionals adjudicate such appeals; in other countries (for example, Norway and the Netherlands), there are independent gatekeepers. Although lodging an appeal requires bureaucratic skill, care recipients (and their care-providers) who lack resources can receive aid from client organisations and from their own care providers, with whom they have a shared interest in challenging the cuts.

This article asks why most people newly deemed ineligible for publicly financed long-term care do not appeal. We present a Dutch case study wherein tighter eligibility criteria led to reduced care entitlements for around 120,000 disabled and elderly people.

### Retrenchment measures

Our analysis focuses on a recent piece of Dutch legislation, the so-called *Awbz-pakketmaatregel* (hereafter 'the reform'). Enacted between 2009 and 2010, it includes tightened eligibility criteria for personal aid with daily tasks such as shopping, administration, making social contacts, structuring one's day and/or group-based activities, such as day care for the elderly. The tighter criteria apply to both current clients and future applicants. Of the 230,000 persons previously receiving care, 60,000 lost their entitlements entirely and even more had their entitlements reduced (CIZ and HHM, 2008). A survey among 500 affected clients revealed that 45 per cent were already experiencing, and a further 15 per cent foresaw, problems due to the reform, including

reduced psychological well-being, less time spent outdoors, having fewer social contacts and increased dependence on their personal networks (Grootegoed and van Dijk, 2012).

Individuals adversely affected by the reform had the right to appeal.<sup>1</sup> After re-assessment by the independent needs assessment centre (CIZ) by means of a telephone survey that categorised one's care needs under the new criteria, affected clients were informed about the decision on their new care entitlements in a letter that also outlined the option to appeal against the CIZ. In the wake of the reform (2009–2010), an estimated additional 10,000 appeals were lodged, that is by less than one in ten affected clients (VWS, 2010). Between one-fifth and one-third of those who appealed had their care reinstated (CIZ representative, January 2011). Although scholars have reported that appeals-making in absolute numbers is on the rise due to the more general trend of consumer empowerment, the limited number of appeals relative to the number of all dissatisfied clients is representative for appeals systems in healthcare settings (Allsop and Jones, 2007).

While welfare state retrenchment usually targets future claimants, the *Awbz-pakketmaatregel* also reduced *existing entitlements*. We therefore surmise that many of those affected believed they had a right to care, which, together with their perceptions of need and opportunities to appeal, would encourage them to protest. The re-assessment of care recipients as 'undeserving' can also be seen as a strategic attempt to shame them for having used (excessive) welfare assistance in the past; much as the insult could well be expected to trigger action in response (Jasper, 2006: 42). The question, then, is why such a small fraction of those who reported experiencing problems due to the cutbacks made use of their right to appeal.

### Factors inhibiting appeal

Living a life of chronic illness or disability and reliance on long-term care often leads to low self-esteem (Schneiderman *et al.*, 1989) and social stigma (Goffman, 1963; Susman, 1994). While the prospect of stigma may discourage people from turning to welfare in the first place, here we want to address a different question: why people who are already in the system do not defend their existing entitlements in the face of cuts and shifting eligibility criteria.

Reasons for not lodging an appeal can be manifold. Taylor-Gooby and Hastie (2003) found in the UK that people with higher education and income more readily expressed dissatisfaction with falling standards in the National Health Service. Other factors correlated with the expression of dissatisfaction included relatively young age and support for opposition parties. Research based on factor modelling and statistical analysis, assuming more or less rational actors, has produced extensive lists of factors contributing to the non-use of social provisions (for example, Van Oorschot, 1995; SCP, 2006). Here we want to know why people do not feel able or justified to mobilise. Crucially, we need to focus on the intersection of emotion and argument, a line of inquiry that has also been employed by some social movement scholars in studying how and why people (do not) start acting, complaining and protesting. The relationship between emotions and social movements (Goodwin *et al.*, 2001) involves both macro- and micro-level processes. On the macro level, the social production of loyalty and trust serves to 'cement' social structures (Flam and King, 2005), while on the micro level, overcoming individual shame or turning anger against the authorities helps mobilise aggrieved individuals.

The approach we follow builds on Hochschild's work on managing emotions (1979, 2003) and its application in social movement research (Bröer and Duyvendak, 2009, 2011). Hochschild argues that people adjust their emotions to what is considered appropriate within specific social situations, referring to the implicit 'feeling rules' and 'framing rules' that govern these situations. 'Feeling rules' are 'guidelines for the assessment of fits and misfits between feeling and situation'; framing rules are 'the rules according to which we ascribe definitions or meanings to situations' (Hochschild, 1979: 566). Applying this framework to the 'right to care' in retrenching welfare states, we would expect from affected citizens a combination of claims to entitlement and attempts to adjust their feelings to the new realities. That is, we expect citizens to 'read' policy changes in ways that foster or inhibit anger, shame, fear, trust and loyalty.

The emotion management perspective has rarely been applied to changing welfare policies (see the introduction to this Themed Section). One study close to our own by Aronson (2006) followed the lives of Canadian women facing home care rationing. In most cases, the (elderly) women were severely hit by cut-backs but did not complain, in many cases not even to the interviewer. But, over time, Aronson was able to observe how these women were silenced and/or silenced themselves, or, to put it more neutrally, how they brought their feelings in line with what they thought was the (new) cultural norm. Non-complaining women often did not want to burden others and were ashamed to display their needs and be seen as complainers; external pressure stifled feelings of unfairness and encouraged feelings of fear and shame. Without making it explicit, Aronson showed how new feeling rules implied in policy enter into management of the self.

The current study focuses on the emotional dynamics of inhibited appeals-making in our era of welfare state retrenchment. In what follows, we ask which feeling and framing rules inform the thoughts and behaviour of people facing cuts to their long-term care in the Netherlands.

## Methods

Our findings are based on thirty interviews with affected clients who reported problems after implementation of the reform. The reform was enacted between 2009 and 2010; the research was conducted between January and June 2010. Based on client consent, municipalities received names, addresses, year of birth and the duration and reduction of care entitlements from the CIZ. In order not to exclude people who did not consent to conveying their personal details to the local authorities, we asked care providers to request the participation of clients who matched our selection criteria. We selected forty-five clients of various ages and care needs in six medium-sized Dutch municipalities whose entitlements to care had been more than halved due to the reform. We included individuals with care entitlements of varying duration (minimally six months) and excluded persons whose entitlements would have been re-assessed without the reform. Clients who did not report strains due to the cuts were also excluded.

The final sample consisted of thirty individuals aged ten to ninety-one experiencing problems with self-reliance and social participation due to old age (nine), cognitive disability (eight), psychiatric need (seven) and physical constraint or chronic illness (six). In the case of a young child, a parent served as the spokesperson. For respondents with cognitive disabilities, relatives or care providers were usually present during (part of) the interview. The respondents all lived independently and received care in kind or via a

cash-for-care scheme that allows clients to purchase care privately with a personal budget. Despite varying levels of education, respondents' incomes were low to moderate; adult respondents mostly received social assistance due to their inability to work.

The face-to-face interviews were held in people's homes and lasted two to three hours. In the semi-structured questionnaire, we asked for a short history of how the respondent entered public long-term care and the impact the reform had on their care arrangements and daily lives. We then asked each respondent how they experienced the re-assessment procedure and whether they had considered appealing the authorities' final decision to cut off (or part of) their care entitlement. For the thematic content analysis of interviews, we used the qualitative data analysis and research software AtlasTi. We first coded respondents as accepting or objecting to the cuts (that is lodging an appeal) under the new rules, and their relative success in retrieving their former entitlement. We deductively examined both traditional, more rational explanations (resources, chance of success), and 'emotional' accounts (reported feeling rules) of why our informants acted as they did. Inductively we constructed types of emotions and feeling rules.

### Three ways to manage shame

Of the thirty clients who found the reduction in care problematic, six formally appealed while twenty-four did not. Of the six who appealed, two had their previous entitlements restored. None of the respondents answered the question 'Did you deliberate over making a formal appeal?' with a purely rational account of their available resources or chances of success. Interestingly, respondents who did not appeal more often related their acceptance to feeling rules than to rational explanations. We found three types of feeling rules, relating respectively to one's dignity, to more needy (deserving) citizens and to the authorities. For each, the greatest obstacle to lodging an appeal was the 'sanctioning' emotion of shame, or more precisely, the *threat* of feeling shame (see Flam, 2005). Shame, described by Scheff (1988, 2000, 2003) as a 'bond affect' that influences all aspects of daily life, evolves from viewing ourselves through the eyes of others. Shame can arise from the disgrace of deeply felt social stigma, but also from the more commonly perceived failure to conform to social norms. We therefore analyze shame in its broadest sense, with references to social stigma, disloyalty and ingratitude as its indicators.

#### *Shame and the desire to be autonomous*

Lodging an appeal was seen, especially by older people, as an admission of being overly dependent on others. While such fear of 'losing face' was likely an issue before the cuts, it had not deterred them from requesting public aid. But now, it kept them from appealing against cuts to their entitlements. An elderly woman (eighty-eight) who decided not to appeal stated:

My care provider advised me to make an appeal, but they are just the new rules. I am *not going to beg* for care, I want to be helped, but in a normal way, I do not need preferential treatment. I am just like every other person.

She perceived appealing as synonymous with begging, while her fear of shame centred on not being 'independent'. It suggests that the threat of shame is greater when

requests for care are reviewed on a case-by-case basis rather than by uniform rules. An elderly woman whose day care was discontinued answered:

Interviewer: Did you consider making an appeal?

No, I am *not going to beg for it*, either I can get it or I cannot. If not, then it stops for me.

Interviewer: What does the reform mean to you in practice?

That I haven't been outdoors since Christmas . . . [continues talking about how she misses day care]. But I still try to do as much as possible by myself. I may be disabled but I am still partially independent.

Although the elderly woman struggles with the reform's effects, she maintains her pride by refusing to 'beg' for care. Working on an 'internal reputation' (Jasper, 2006) apparently requires one to accept care only when the terms of its provision are universal. Having to prove that one is an 'exceptional case' is not in line with the shame management of chronically ill or disabled people who desire to be autonomous.

#### *Shame and social comparison*

The intention behind the reform of preserving care for the most severely disabled was systematically communicated within the policy field, the care sector and the media. The cuts were presented as necessary, especially in a time of economic crisis. In deciding how to feel about the cuts, respondents made subjective comparisons to people whom they considered 'worse off'. When asked how she feels about her reduced entitlements, a thirty-eight-year old woman with a cognitive disability receiving pedagogical assistance replied:

Well, I am glad that I still receive care, but if they [the government] only care for people who really need it, then I would prefer that others receive more care, and I get less, you see what I mean?

This reference to 'the hardest hit' often informed how affected clients felt about appealing. As a twenty-one-year old woman with a chronic illness whose personal budget was halved explained:

Yes, I feel bad about the cuts, not only for myself but also for the many others who lost their care. But at least I still have a personal budget. At the riding school [for the disabled], I heard that there are a lot of people who no longer have anything. That is why I say: you will not hear me complain. If I did complain, I think that would be unfair to others. *I would feel ashamed to appeal*, I seriously mean that. If I hear and see what others have, then I think I cannot complain. If I succeed in retrieving my full budget, then another would get less.

This argument reproduces the zero-sum logic of the policy. The woman 'feels bad' but does not complain. Threatened by shame when she thinks of those who are worse off, she manages her emotions. A forty-eight-year old man suffering from psychosis even tried to feel grateful as he compared himself to poorer people:

Well, if you see how the poorest people live in Europe, then I think I am reasonably well off. I have food, shelter and a bed. You see, because I see that it can be worse, I think that *I should feel grateful* for what I have, and that keeps me from appealing against the reform.

These respondents only compared themselves to people worse off than themselves, not only to the 'hardest hit' but also to people who do not live in welfare states, currently or in the past. In this way, respondents could place their own grievances in perspective and ward off feelings of relative deprivation (Morrison, 1971). Identifying with the most severely disabled persons, we surmise, would undermine their attempt to maintain an autonomous identity.

#### *Shame and demand for gratitude*

Social institutions inevitably set norms around disputes as their representatives tell citizens how to address their grievances (Felstiner *et al.*, 1981). The interviews revealed that clients felt trapped between their own perceptions of the problem and the information they received from the CIZ, that is that their care need is no longer (fully) a *public* concern. A mother of two autistic children (aged thirteen and fifteen) whose personal budget was reduced stated:

On the one hand, I can understand it, they [children] also become older and more independent, but when I see how much extra work and related costs their disability creates I think it is very unjust . . . I thought about making an appeal, but the CIZ person told me that it is 100 per cent sure that I will not retrieve the previous assessment. The rules have become stricter, and they [CIZ] tell me that it [the problems] is considered part of their puberty now. She [CIZ official] says 'you have no grounds to stand on' and so *I tell myself that I should just feel grateful* for what [care] remains.

The above passage clearly shows that this mother manages her feelings to try to bring them in line with the new policy. Gratitude towards the authorities is what she thinks she should feel – not anger, indignation or being seen as a person who asks for too much.

Appealing was also inhibited by officials emphasising the integrity of the re-assessment procedure. A mother of a twenty-two-year old daughter with a cognitive disability whose personal budget was halved stated:

For a long time, we did not have to worry about finances, but now we do, and we worry about that a lot, and if you do not have a solution, it eats away at you. It also feels unfair that at first you are encouraged [by the government] to use a personal budget to arrange care in a private setting, and when you have done so, they take away the money. I mean, if I would request intramural care for my daughter, she would without a doubt get it.

Interviewer: Did you consider making an appeal against the cutbacks?

Well, I might have if I felt that I was mistreated, but how the CIZ spokesperson explained the new rules made me think that she cannot do anything about it. I trusted her, because she seemed a nice person. I had the feeling she understood my problems, so *I felt that I had to accept it*.

The former recipient of publicly financed care again downplays her indignation. Instead she reaffirms her trust in the authorities, backed by the construct of a 'nice person'

who 'understands' when she is told that there is no other way. Here client loyalty to the authorities (and the threat of being seen as disloyal) encourages acceptance, while the showing of empathy by authority figures appears as an effective strategy to regain client trust and to cool feelings of anger and frustration (see Goffman, 1952). This finding differs significantly from studies on poverty that have traced clients not claiming their social rights to the degrading treatment of their claims (for example, Corden, 1987).

By adopting the moral frame of reference of the care authorities, respondents' experience of indignation does not develop into anger and/or the use of the right to appeal. The care that is still received is presented by the authorities as a 'gift', to not accept it with gratitude is to undermine the underlying social bond, risking shame (Hochschild, 2003). The respondents' reasoning goes beyond so-called 'shielding stories' (ibid.) that cover up their lack of agency and its attendant dishonour. Rather, indignation is mediated by (a fear of) shame; one has to appreciate the care that is still received, despite being labelled as a relatively 'undeserving' welfare recipient.

In sum, we find that making use of the right to appeal is inhibited by the shame or anticipation of shame that arises when one is no longer able to perceive oneself as a relatively independent person, a sociable peer and good citizen who is loyal to the authorities and their new moral rules.

### **Dodging shame: pathways to the right to feel angry**

A minority of clients who were labelled as having a relatively mild disability and had their care entitlements reduced lodged an appeal. They often experienced the re-assessment as illegitimate. An elderly woman (eighty-two) recounts her experience of a telephone interview and her path to anger:

I was phoned by CIZ for the re-assessment and was asked some general questions about my mobility and so forth. I noticed that the woman on the phone needed to follow a strict procedure, not leaving room for personal specifications, but when I found out I was actually talking to an unskilled call centre employee I became *really mad!* That was so degrading and inhuman.

The above passage reverses the reform's attempts to shame and blame; it is the authorities who should feel ashamed, not clients with 'mild' care needs. Such anger over-rides officials' attempts to justify the reform and inhibit protest by cultivating citizen 'loyalty'. Those who appeal believe they are victims of the reform, made necessary by external actors such as the greedy rich or blundering politicians, an attribution not often made by those rejecting the right to appeal. A fifty-eight year old woman with physical and psychiatric problems stated:

My opinion is that we [people with care needs] have to pay for the mistakes of the bankers. They request loans from the government, not us. We have nothing to say about that. We stand offside. But now we *have to pay*, because we lose our welfare support, and I think that is unfair.

The woman redefines the situation in a way that circumvents loyalty and shame and that legitimises anger: cuts to public services should not be made on the backs of the innocent in society. Pointing to external villains redirects blame from oneself, thereby



evading (the fear of) shame (Jasper, 2006: 51). Scheff (1988) suggests that mostly people with high self-esteem are most capable of evading shame; high self-esteem may also lessen the need to defend an autonomous identity. Still, these people must make peace with the issue of solidarity with fellow citizens. A middle-aged man with a physical disability, who managed to retrieve his care assessment by appealing, was asked by the interviewer how he felt about others unable to do so:

Well, lately I hear about that on the news, about an elderly woman who went to day care for six years, with no friends or relatives left. She can no longer get to day care as of January, and is stuck behind the geraniums. That is terrible! *It makes me angry*. Because she is not so assertive, she cannot appeal. Well, luckily I am . . . In the end, I made an appeal on advice of my brother. He said to me, you need to ask for a personal hearing; the official needs to see you in person and you should be able to tell your story.

From this perspective, appealing against the decision of the authorities remains the right thing to do, regardless of whether other (possibly more needy) individuals do so or not. They do not reason as if they are cutting the same cake. When a client's denial of (the fear of) shame is supported by friends and family, when lodging an appeal is not synonymous to begging but the 'proper thing to do', shame can be acknowledged and over-ruled. In some cases, it becomes the authorities who should feel ashamed.

### Conclusion and discussion

Recent reforms of the welfare state have pressured citizens to organise long-term care within their private networks. The current redistribution of care rights builds on the distinction between relatively mild and critical care needs and preserves rights only for 'those who really need it'. To enact this divide, around 230,000 LTC clients in the Netherlands were re-assessed under the stricter criteria of the reformed Exceptional Medical Expenses Act (AWBZ). Sixty thousand people lost their entitlements to care entirely, while even more individuals, most often the elderly and people with psychiatric or cognitive disabilities, had their entitlements reduced (CIZ and HHM, 2008). Many affected individuals reported increased dependence on their private networks, reduced psychological well-being and less time spent outdoors (Grootegoed and van Dijk, 2012). Still, only a minority made use of the readily available opportunity to appeal against the decision of the independent needs assessment centre (the CIZ).

Emotions were central in our respondents' decisions not to appeal; none mentioned that they lacked the ability to do so. Those who did not appeal were, broadly speaking, too ashamed to do so, going to great lengths to avoid the risk of (further) stigmatisation, of depriving other fellow citizens of care, or of showing distrust and disloyalty towards the authorities. In contrast to the common perception that not making use of the right to appeal is a 'failure' on the part of dissatisfied clients (Mulcahy and Tritter, 1998), our findings show that clients resisted appealing so as to manage their reputations and to avoid shame.

The fear of shame follows from seeing oneself in the eyes of others and prompts people to adjust their conduct and emotions accordingly. Older and chronically ill people did not want to risk potential shame by appealing. The shame of social stigma was evident as they did not want to be perceived as 'begging'. They refrained from identifying with

people receiving more care as this would imply that they were among the 'most severely disabled'. They would rather become isolated than admit inability to manage their daily lives. Distributed on the basis of the severity of need, claiming the right to care today is a different matter than when these clients entered public care, then seen as a right of citizenship. They thus preserved their dignity by not asking for more than they were judged entitled to by the needs assessment centre.

Affected clients also distanced themselves from other, perhaps needier persons. In this way, they could see themselves as relatively independent and loyal to the authorities. These feelings were not self-evident; they emerged through interactions with the needs assessment centre and through comparison with other affected clients, which inhibited feelings of relative deprivation (Morrison, 1971). During their re-assessments, the needs assessment centre discouraged clients by referring to the slim chance of successful appeal and the reform's aim to preserve care for the genuinely disabled. When clients compared themselves to needier individuals, they actively downplayed their anger, feeling ashamed to claim their rights. At least they had 'a roof over their heads'.

When clients did appeal, they managed their emotions differently. Referring to organisational misconduct and external causes for the reform legitimised their anger, as did a refusal of the logic of the welfare cuts. They were encouraged by family and friends, who assured them that lodging an appeal would not threaten their autonomous identity but would instead empower them. Interestingly, those who chose to appeal were not discouraged by thinking of the plight of others, but felt inclined to fight for their 'own' rights.

Avoiding shame proved a crucial concern for disabled and elderly persons who already felt that they had to defend their dignity. If policy states that only the 'truly needy' deserve publicly financed care, this raises significant emotional hurdles to individuals who, against the evidence, resist identifying themselves as 'truly needy'. Our analysis has shown that the risk of (the eminently social) emotion of shame cannot be battled alone; the new policy norm to feel solidarity with the 'hardest hit' can only be breached when one's family and friends affirm that it is proper to feel angry. Rather than any objective criteria of deservingness, we may say that making use of the right to appeal has more to do with one's ability to take distance from (the fear of) shame.

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## Notes

1 No financial costs are involved in lodging an appeal against the needs assessment authority. Only when the client disagrees with the outcome can he or she take further legal steps, which involve financial costs.

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