Carers and the Social Services and Well-being (Wales) Act 2014 Luke Clements Cerebra Professor Law & Social Justice School of Law, Leeds University www.lukeclements.co.uk

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Programme

Part I ~ An overview;

 Definitions and principles; assessing the care & support needs of carers and disabled people;

Part II ~ Carers rights under the SSW-b (Wales) Act 2014;

Meeting 'eligible needs': care and support;

Part III ~ Parent carers and young carers;

Part IV~ Common problems

• Covid-19 impacts; carer / disabled person conflict: equality & human rights

Part V ~ The Eligibility criteria in greater detail; Resources (single slide).

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Part I	-
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Background / overview	
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Definitions & principles	
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Definitions

People who may need care and support

 The need must arise from physical or mental illhealth, age, disability, dependence on alcohol or drugs,

The Care and Support (Eligibility) (Wales) Regulations 2015

Carers

 A person who provides or intends to provide care for an adult or disabled child (but is not paid to do so)

Social Services and Well-being (Wales) Act 2014 s3

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Well-being ~ section 2

Well-being means any of the following:

- physical and mental health and emotional well-being;
- protection from abuse and neglect;
- education, training or recreation;
- · domestic, family and personal relationships;
- contribution made to society;
- · securing rights and entitlements;
- · social and economic well-being;
- · suitability of living accommodation.

for adults

- · control over day to day life;
- participation in work

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Well-being ~ section 6

LA must have regard to-

- the individual's views, wishes and feelings,
- promoting and respecting the dignity of the individual,
- the characteristics, culture and beliefs of the individual (including, for example, language), and
- the importance of support to enable the individual to participate in decisions....
- for adults
- the presumption that they are best placed to judge their well-being, and
- · the importance of promoting independence if possible

Assessing the care and support needs of carers and disabled people

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Assessment duty - overview

Carers assessments and the assessments of disabled people should 'feed into each other'.

- A carer's assessment might identify the need for a carer to have a 'break' – because, for example, they are unable to continue providing the same level of care;
- The disabled person is then assessed to identify the additional care s/he needs to enable the carer to have a 'break'.
- The carer's assessed need is for a 'break'
- The disabled person's assessed need is for the additional support required to enable the carer to have the break (ie a sitting service / respite care etc).

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Assessment duty - general

Duty to assess disabled adults (s19); children in need (s21); and carers (s24).

- Duty triggered by the 'appearance of need' (not a request);
- · Finances are irrelevant;
- · Level of need is irrelevant;
- Adults can refuse an assessment unless they 'lack capacity' to refuse or are at risk of abuse or neglect
- Key Guidance 'Part 3 Code of Practice assessing the needs of individuals'

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The purpose of an assessment ... is to work with an individual, carer and family ... to understand their needs, capacity, resources and the outcomes they need to achieve, and then to identify how they can best be supported to achieve them.

At the core of this is a conversation about promoting independence and development by maximising people's control over their day to day lives ...

Part 3 Code, para 11

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Assessments - Code of Practice

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Assessments - Code of Practice

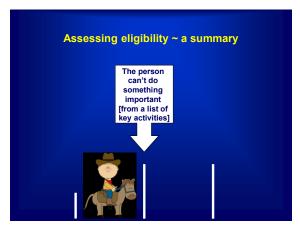
independence

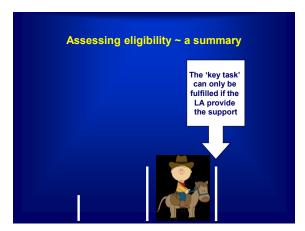
Well-being is defined in relation to all aspects of a person's life. For a person who needs care and support and a carer who needs support it is intended that well-being includes key aspects of independent living, as expressed in the UN Convention on the Rights of Disabled People, in particular, Article 19 of the Convention.

Part 2 Code of Practice (General Functions) para 56

Assessing eligibility ~ a summary Regulations specify a process for assessing whether a disabled person / carer is eligible for support • These 'eligibility criteria' regulations are highly technical and unnecessarily complex • These are considered in greater detail at the end of this talk (section 7 below).









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Assessing need

"What if"

- What will happen if care and support is not available?
- The greater the risk to the person's well-being the greater the onus is on the LA to meet that need – or to give cogent reasons as to why this is not necessary.
- Well-being includes physical, mental, social and emotional well-being as well as the ability to engage in employment, education, training, leisure and social activities.

Assessing eligibility ~ a summary

- the disabled person / carer is unable do key tasks themselves;
- 2. there is no-one willing / able to help them; and
- 3. no community resources able to do this either

Even if someone is technically able to something themselves, this is ignored if it would:

- · cause then significant pain, anxiety or distress;
- endanger health / safety; or
- take significantly longer than normally expected
 The Care & Support (Eligibility) (Wales) Regs 2015 reg 6.

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Assessing eligibility ~ a summary

Key tasks such as:

- eating, keeping clean, getting dressed, preparing meals keeping home clean, moving around safely
- involvement in work, education, learning, leisure;
- maintaining personal relationships and involvement in the community;
- · caring for a child;
- being safe from abuse or neglect;

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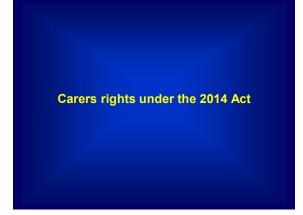
Copies of assessments and care plans

The individual / their authorised representative and /or parents must be given a copy of:

- their assessment
- Assessment Regs 2015 reg 6
- all elements of the assessment and eligibility as well as their care and support plan

Part 4 Code paras 24 and 95.





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Overview

The Act places a duty on social services:

- To promote the 'well-being' of carers who need support (s5);
- To assess the support needs of carers (adult carers, young carers and parent carers) (s24);
- To assess the extent to which carers are willing and are able to provide (and to continue to provide) care (s24);
- To provide support to meet carers' eligible needs.

Carers' assessments

Carers do not have to 'request' the assessment it should be done as soon as a council is aware of their caring role (section 24);

In order to have an assessment, carers do not have to be providing 'regular & substantial' care (section 3);

There is a 'duty' to meet carers' 'eligible needs'

- for carers who are adults (section 40);
- for carers who are under 18 ie young carers referred to as 'child carers' (section 42).

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Combined assessments

For adults

 A carer's assessment can only be combined with a disabled person's assessment if they both agree (s28);

For young people under 16

 Assessments can only be combined if the parent and child agrees (s28);

Unless the council 'is satisfied' that (1) the child lacks capacity to agree and (2) a combined assessment is 'consistent with the child's well-being';

But it is unclear if the parent must also agree to a combined assessment in such cases (s28(6))

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Carers' assessments

What is 'care'?

- Both practical and emotional support: section 2(2)(a) 'physical and mental health and emotional well-being'
- Previous guidance has referred to carers who may 'not be physically or practically caring at all at certain times, but still be anxious and stressed waiting for, or actively seeking to prevent, the next crisis.

Welsh Assembly Government Guidance 2000 Act (2001) para 4.11

Basic principles

There is no duty to care for family members – this Poor Law obligation was abolished by the National Assistance Act 1948 section 1.

Councils must:

- not assume that a carer is able and/or willing to provide (& continue to provide) care (s24);
- assess the impact on a carer's 'well-being' of providing (& continuing to provide) care (ss 2 & 6);
- identify the outcomes a carer wishes in their day-to-day life (s24);
- Identify whether the carer works or wishes to (and / or) to participate in education, training or recreation (s24).

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Carers: willing and able

The ability and willingness of a carer to care must be recorded explicitly

Part 3 Code of Practice (assessing the needs of individuals) para 120

It can be difficult for a carer to say that they are not willing to provide care. In such cases it could be states that:

- It's not a question of 'being willing' the plain fact is that
 they are simply unable to provide care unless the
 authority first determines that the individual is eligible.
- Then, and only then, will they be able to discuss the nature and extent of the care (if any) they might be willing to provide.

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Carers: willing and able

In making a determination of eligibility there should not be an over reliance on any voluntary caring arrangements. Local authorities must ensure that the ability of the carer to provide care is sustainable and that they comply with their general duty to promote the well-being of the carer and the person cared for.

Part 4 Code of Practice (Meeting needs) para 36

Willing and able

A 2018 ombudsman complaint concerned a disabled person who had a mobility car. Although he was unable to drive it, the council decided that his parents should drive it – taking him to and from his day centre.

 The ombudsman held that it was maladministration for the council to have failed to consider the impact that this would have on their health, their loss of respite care and whether they were willing and able to do this.

Nottingham City Council (18 004 245) 2018 See also Wiltshire County Council (16015946) 2018

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Willing and able

Local Government Ombudsman (2016)

- Authorities must not assume a carer is willing or able to provide any care – including additional care arising from a reduction in the care package.
- It will be maladministration for a reduction to occur without assessing the carer and explicitly clarifying (and recording) whether she/he is 'able and willing' to provide the additional care.

Complaint London Borough of Bromley 7/9/16

 LA Local authority reduced adult in needs support without proper consideration of the impact on his carer.
 Complaint Essex CC 30//11/16

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Meeting eligible' needs: care and support

Meeting eligible needs

Authorities can meet needs in many ways:

LAs must meet the needs of people assessed as eligible (ie carers or disabled people) (sections 35, 37, 40 & 42)

- (1) By providing (or arranging) support to be provided to the disabled person or a carer;
- (2) Examples of support include:
 care accommodation; care and support at home or in
 the community; services, goods and facilities; social
 work; direct payments; aids and adaptations etc etc

section 34(1) & (2)

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Respite / short breaks

The duty to meet the needs is 'non resource-dependent'.

ie if the assessment identifies a need for (say) 10 hours of sitting services a week, or of one weekend a month for the child to be accommodated away from the home – then this need must be met precisely and it is not something that the LA can 'trim' because it has to make cut backs due to resource shortages.

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Respite / short breaks

A 2016 ombudsman report

- Adult with LD lived with his parents. His care package had for many years included 50 days of replacement care to enable his parents to have a break.
- On review this was reduced to 14 days although his needs had not changed and the sustainability of his parents in maintaining their support was recorded as at risk.
- In finding maladministration the ombudsman held that the LA had to provide an explanation as to the reasons for the reduction: that it 'needs to show what circumstances have changed to warrant this reduction in respite provision'.

Respite / short breaks

It was not acceptable for the council to state that it would offer emergency respite if the need arose:

- The parent's need for 'weekends away and a little social life are not emergencies but part of a planned sustainable support regime'.
- The Council's assessment does not address these sustainability issues ... the impact on the carers' daily lives and non caring activities must be included.

Complaint against Sefton MBC 23 Aug 2016.

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Carer specific support

Local authorities can provide all manner of supports directly to a carer. Although the Welsh guidance is silent on this point, the English guidance suggests, that this could include:

 relaxation classes, training on stress management, gym or leisure centre membership, adult learning, development of new work skills or refreshing existing skills (so they might be able to stay in paid employment alongside caring or take up return to paid work), pursuit of hobbies such as the purchase of a garden shed, or purchase of laptop so they can stay in touch with family and friends.

Statutory Guidance to the Care Act 2014 para 11.41

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Carer specific support

Carer's Travel expenses

In 2015 High Court proceedings the Secretary of State confirmed that carers services under the Care Act 2014 'could include help with fares when travelling to the recipient of the care'.

Hurley v. SS Work and Pensions [2015] EWHC 3382 (Admin) para 25

The SSW-b (W) Act 2014 is – in this respect - indistinguishable from the Care Act 2014

Direct Payments

Sections 50 - 53

- Where care / support is identified as being required, the person who is eligible has a right to have this paid as a 'direct payment'.
- The Care and Support (Direct Payments) (Wales) Regulations 2015 contain the detail.
- Direct payments can now be used to purchase care and support ... from any person (including, among others, the authority which made the payment).

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Direct Payments

Ombudsman's reports

- 2018 report found maladministration where a council sought to recover DP monies spent on birdwatching and gardening equipment when the assessment identified the need as being to access community activities.
 No 17 013 291 (Norfolk CC)) 24 April 2018
- 2018 report concerned a DP used to provide respite care to enable a husband to pursue his walking hobby
 - No 17 011 713 (Kirklees MBC) 26 Sept 2018
- 2018 report concerning pet care costs
 No. 13 014 946 (Central Bedfordshire C) 15 Jan 2016

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Parent carers

Section 24 places a duty on the LA to assess:

- When a carer is providing support for an adult or disabled child who is based in the LA area;
 - The assessment must consider
 - whether carer has a need for support; and
 - what those needs are.

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Parent carers

s24 is clear, that authorities must:

- assess the extent to which the carer is able / will continue to be able, to provide care;
- assess the extent to which the carer is willing, and will continue to be willing, to do so;

s21(7) states that a disabled child is presumed to need care in addition to, or instead of, the care and support provided by the child's family.

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- Single mother with two children: one with significant disabilities & in need constant supervision.
- Council advised her that it expected parents to organise their work responsibilities around the needs of their children: that it was not its responsibility of to provide direct payments solely to enable parents to work
- But she could use the respite breaks she received to enable her to work

A 2016 ombudsman's report

Maladministration

- · Council has failed to understand the law.
- The child's assessment and carer's assessment should 'feed into each other'.
- Council knew son needed constant supervision.
- Council also knew mother in full time work and the nature of her job meant she could not pursue flexible working.
- These were key factors but neither the son's assessment nor the carer's assessment properly considered those issues

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A 2016 ombudsman's report

- Government guidance clearly states authorities should not assume a carer is happy to continue in their caring role.
- Councils are required to consider whether a carer wishes to work.
- Nothing in the assessments to suggest the Council properly considered the impact on ... if she did not receive support during school holidays.
 - Kent County Council No. 14 015 230 7 June 2016.

A 2007 ombudsman's report

A parent sought DPs to enable him to purchase respite care for his young son, so that he could pursue his University's studies.

The council required parent carers to give reasons why they wanted DPs (in lieu of services) and stated that in any event:

 DPs could not be paid for childcare as childcare was the responsibility of the parents, whether or not children have a disability'

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A 2007 ombudsman's report

The ombudsman held that:

 there is an obligation on local authorities to ensure that parents are not 'disadvantaged in pursuit of education/training any more than other parents'.

Complaint No. B2004/0707/S/370 (Swansea CC) 22 Feb 2007

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Young carers

Section 42 places a duty on LAs to meet the needs of young carers (termed 'child carers') if the person for who they care is based in the LA area and the YC meets the standard carers' eligibility criteria.

However if the YC's needs are addressed by providing additional support to the person for whom they care, then the duty only arises if additionally that person satisfies the financial eligibility rules (s42(4)) and (overly complex) mental capacity criteria (s43).

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Young carers

Carers under 18 who provide care for a disabled adult / child (unpaid and not as 'voluntary work') section 3

- Young carers should not have to carry out significant caring roles – be that for a sibling or a parent – etc.
- Best practice requires that where a young carer is found to be providing significant care for another, the social services should make arrangements for the person needing care to have adequate support so that the young carer stops having to provide this care

Young carers

- LAs must, seek to identify the outcomes that YCs wish to achieve (s24(4)(d)) 'to the extent' that it is 'appropriate having regard to the carer's age and understanding', as well as their parents views on this and their well-being generally (s24(4)(d)).
- A YCs assessments must also pay particular regard to the developmental needs of the child, and whether it is appropriate for the child to be providing the care at all (s24(5)(c)).

Young carers

- As with the assessment duty owed to disabled children, (s21(6)) the way a carer's assessment is undertaken should be 'proportionate in the circumstances' (s24(7)).
- Proportionality goes to the scope and depth of an assessment – and not (of course) to the question of whether one is undertaken: the duty to assess (where a need may exist) is obligatory.

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Young carers

- The assessment ... must have regard to whether the carer works or wishes to work and whether they are participating or wish to participate in education, training or leisure activities.
- [for YCs] the assessment must have regard to his or her developmental needs and the extent to which it is appropriate for the child to provide the care.
- This should lead to consideration by the LA of whether [the YC] is actually a child with care and support needs ... who ... should be assessed under s21.

Part 3 Code p7 and Part 4 Code para 50.

R (E) v. Islington LBC (2017)

- Child had to translate into sign language for her deaf mother (& vice versa) and provide extra care for younger siblings;
- LA considered this 'highly inappropriate';
- LA accepted she had caring 'responsibilities beyond what is appropriate' but argued that these due to her mother's inadequate parenting;
- LA refused to undertake a YC assessment;
- Held
- illogical she was catering for needs arising out of her mother's deafness, even if mother's approach to parenting may have been a contributory factor.

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Covid-19 Coronavirus Act 2020 s15 & Sch 12 Part 2 Significant volume of WG guidance eg Welsh Government Visits to care homes: guidance for providers 2020 Welsh Government Adult social services during the COVID-19 pandemic: guidance 2020 Welsh Government Children's social services during the COVID-19 pandemic: guidance 2020

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Covid-19

Welsh Government Adult social services during the COVID-19 pandemic: guidance 2020

... authorities should continue to do everything they can to continue meeting their existing duties prior to the 2020 Act provisions coming into force

The fundamental principles of the social care approach remain unmodified:

- prevention and early intervention increasing preventative services
- voice and control putting the individual and their needs, at the centre of their care ...

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Covid-19

Welsh Government Adult social services during the COVID-19 pandemic: guidance 2020

The guidance refers to (and endorses) the English Department of Health document 'Responding to COVID-19: the ethical framework for adult social care' (2020) which contains, as a key principle 'flexibility':

 This principle is defined as being responsive, able, and willing to adapt when faced with changed or new circumstances. It is vital that this principle is applied to the health and care workforce and wider sector, to facilitate agile and collaborative working

Covid-19

Flexibility

Being flexible when care and support is provided; Being imaginative in the use of direct payments (ie carrying over funds from week to week / paying family members etc. Flexibility and visiting restrictions – see eg:

- BP v Surrey County Council & RP [2020] EWCOP 1
- Hertfordshire Partnership University NHS Foundation Trust (2020)

Both concerned outright bans on contact with disabled person – both concerned 'proportionality'

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Covid-19

Reduction in care packages due to Covid

If care and support is reduced due to delivery difficulties – ie social distancing etc – then authorities must not only demonstrate flexibility, they must also reinstate the support as soon as circumstances permit.

Some authorities are suggesting that they will not restore support without a reassessment.

Legally this must be wrong.

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Covid-19

Reduction in care packages due to Covid

There are two key legal presumptions that must apply in such cases:

- 1. that the need continues until the authority has evidence that it does not; and
- that the need must be met if at all possible so if (for example) another way of delivering the support is found or if the rules on social distancing are relaxed – then the support must be reinstated in full and maintained until such time as the authority has cogent evidence that the need has diminished.



The 'cared for' refusing services

A disabled person may refuse services which would be of benefit to the carer – for instance respite care.

Frequently these difficult situations can only be resolved by skilled and sustained social work. The courts have repeatedly held that social services departments cannot take a simple refusal of help at face value. They should continue to try and engage with the person.

eg R v Kensington & Chelsea RLBC ex p Kujtim (1999) & R (Patrick) v. Newham LBC (2000) 4 CCLR 48.

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The 'cared for' refusing services

- At law, where an authority has identified a carer as having eligible needs (but it is not able to meet these needs by providing care and support to the adult needing care) then it must 'so far as it is feasible to do so, identify some other way in which to do so'.
- this is stated explicitly in the Care Act 2014, section 20(8) and must be implicit within the SSWB Act 2014.

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The '	cared	for' ref	fusino	ı services

English guidance on 'whole family approaches'
provides practical advice concerning an elderly person
with dementia who was adamant that she only wanted
her daughter to care for her – and who was herself
'exhausted and at breaking point' – to which an
imaginative approach was taken to work around this
issue.

Department of Health The Care Act and Whole-Family Approaches (2015) pp. 8-9

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Information sharing

On occasions carers are refused access to crucial information concerning a 'cared for' person who lacks sufficient mental capacity to agree to the sharing of the information.

GMC guidance (2017) advises however:

it is reasonable to assume that patients would want those closest to them to be kept informed of their general condition and prognosis

GMC Confidentiality: good practice in handling patient information (2017) para 38

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Carers, equality & human rights law

Associative Discrimination

In Coleman v Attridge Law (2008) ruling by the European Court of Justice held that carers of disabled people were protected from discrimination 'by association'

This exists when a person is treated adversely because they are caring for a disabled person – ie:

- · being dismissed because you have take time off to care;
- being denied a loan because the bank learns you have a disabled person in your household;
- being denied free school transport for your 15 year old disabled son (who cannot walk unescorted to school) because as a parent you should accompany him.

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'Focusing on women caregivers'

'it is hard to think of a human right that is not potentially affected in some way by the unequal distribution and difficulty of unpaid care work' (para 27)

Magdalena Carmona,

UN General Assembly's Special Rapporteur on extreme poverty and human rights 'Focusing on women caregivers' A/68/293 (UN, 2013)

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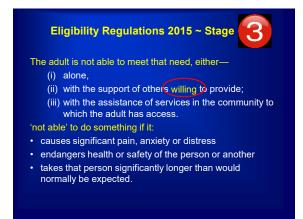
Adults in need and disabled children: The need is due to physical or mental ill-health, age, disability, dependence on alcohol or drugs ...; Carers: The need arises as a result of providing care for either an adult in need or a disabled child



Eligibility Regulations 2015 ~ Stage The need relates to one or more of these outcomes: (a) ability to carry out basic self-care or domestic routines; (b) protection from abuse or neglect; (c) involvement in work, education, learning, leisure ...; (d) maintaining family / significant personal relationships; (e) development & maintenance of social relationships and involvement in the community; in the case of an adult • fulfilment of caring responsibilities for a child; in the case of a child • achieving developmental goals

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Eligibility Regulations 2015 ~ Stage basic self-care ~ tasks part of normal daily life including— (i) eating and drinking; (ii) maintaining personal hygiene; (iii) getting up and getting dressed; (iv) moving around the home; (v) preparing meals; (vi) keeping the home clean, safe and hygienic



Eligibility Regulations 2015 ~ Stage Willing Carers could be advised to: • state that they are not able (and therefore not willing) to provide care unless the LA first determines that the individual is eligible. • that then, and only then, will they be able (and therefore willing) to discuss the nature and extent of the care (if any) they might be willing to provide. As already noted, carer ability and willingness must be recorded explicitly

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'Services in the community to which the adult has access' Does the carer / disabled person have to demonstrate that there are no suitable 'open access' support services available – ie that they have tried various options and these have not worked?; or is it the local authority that has to identify support services that would meet the carer's / disabled person's needs (and so that there is no need for it to have to provide a tailor made package of support for the individual)?

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'Services in the community to which the adult has access' The duty rests with the local authority Code Part 4 32. The eligibility criteria must not be used as a tool to require individuals to demonstrate they have exhausted every other possible avenue of support before becoming eligible for local authority assistance.

The need is such that the adult / carer is unlikely to achieve one or more of their personal outcomes unless— • the LA arranges secures their care / support It is difficult to fully understand the point of this requirement. It is not explained in the relevant Codes (2, 3 or 4) • In almost all cases, once a person has satisfied the first 3 stages, the authority will be under a duty to meet their eligible needs. What are 'personal outcomes'?

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The assessment should identify what are the important things that the disabled person / carer want to achieve. If these come within the scope of a person's 'well-being' defined by the Act, then these will form their personal outcomes. Part 2 Code p.9 contains a diagram that seeks to explain this.

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