



# **Carers (Scotland) Act 2016**

**Report from Stakeholder Development Day, 23<sup>rd</sup> November 2016**

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## **Background**

This report presents the findings from a stakeholder engagement event that took place in November 2016. The event was planned to bring together the members of the Implementation Steering Group for the Carers Act and of the sub groups that have been set up. The participants on the day therefore included carers, COSLA, health and social care partnerships, local authorities, health boards, national carer organisations, and other key organisations.

The points made during discussion have been summarised in the report for brevity and accessibility, but remain true to the ideas and views expressed by participants.

The report is intended to help the Scottish Government, with partners, to inform next steps in preparing for commencement of the Act.

## **Overview of event themes**

The event featured six discussion topics. Participants and group facilitators made notes on the discussions, collated and summarised below (full notes in Appendix).

### **1. Breaks from caring**

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Four main themes emerged in this discussion:

1. Define short breaks by the difference they make (8 comments)
2. Use guidance to ensure choice through flexibility of definition (7 comments)
3. Use regulations to define and support breaks (5 comments)
4. General principles (4 comments)

### **2. Adult Carer Support Plan/Young Carer Statement**

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The comments in this discussion can be separated into those relating to regulation (11 comments), guidance (6 comments), and implementation (3 comments).

Under the theme of 'regulation', the main sub-theme, with 7 comments, is to make the most of existing legislation, regulations and outcome frameworks.

### **3. ACSP/YCS for carers of those who are terminally ill**

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9 themes emerged from the 75 notes that were made under this discussion topic:

- Implementation practicalities (14 comments)
- Informing/identifying carers (11 comments)
- Timescales (10 comments)
- Regulation (9 comments)
- Prioritisation (8 comments)
- Principles (3 comments)
- Assessment (4 comments)
- Triggers (4 comments)
- Language (4 comments)

#### **4. Monitoring and Evaluation**

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8 themes arose from the 76 notes made in this area. The question of what to measure was by far the biggest theme.

- What to measure (41 comments)
- One size doesn't fit all (7 comments)
- Defining carers (6 comments)
- Action (6 comments)
- Sharing good practice and learning (6 comments)
- Complexity (4 comments)
- Collaboration (3 comments)
- Manageable/proportionate (3 comments)

#### **5. Successful Implementation**

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Stakeholder involvement was the biggest theme here, with 32 comments. As with other discussion topics, how the Act fits with other legislation was another common thread, with eight comments. Seven comments relate to resources and eligibility.

#### **6. Eligibility Criteria**

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Six main themes emerged from 57 comments on this topic. The largest theme relates to the principles which should guide the creation and use of eligibility criteria.

- Principles/key issues to consider (18 comments)
- Engaging carers (13 comments)
- Standardisation (8 comments)
- What eligibility criteria should include (7 comments)
- Guidance (6 comments)
- Resources (2 comments)

## Topic 1: Breaks from caring

Four main themes emerged in this discussion:

1. Define short breaks by the difference they make (8 comments)
2. Use guidance to ensure choice through flexibility of definition (7 comments)
3. Use regulations to define and support breaks (5 comments)
4. General principles (4 comments)

15 of the 24 notes related to defining short breaks by the outcome they produce (i.e. not the activity undertaken), with flexibility and choice being the other main theme. Interestingly, two comments identify the need to define what a short break isn't, in order to make sure breaks provide not just time off but *respite*.

**In this section and those that follow, selected quotes are used to illustrate each theme. See Appendix for fuller participant and facilitator notes.**

### **THEME: Defining short breaks by the difference they make**

1. What helps the carer in their caring role?
2. Something that works for both person cared for and carer.
3. Any time spent away from the caring role which allows maximum individual selection use of 'time off'.
4. What should be considered a break? Anything that allows the carer to recharge their batteries. Not time to do things that enable them to care (e.g. housework, paperwork) or employment/education (unless the individual identifies this as their break).

### **THEME: Use guidance to ensure choice through flexibility of definition**

1. Guidance could give examples to meet the needs of the individual carer, allowing for flexibility and choice.
2. Framework strong guidance of choice highlighted. Breaks mean different things to different people.
3. What isn't a break from caring i.e. hospital, work, illness – for guidance, include examples. That is, when someone is ill and person cared for is in respite, so that budget was used and couldn't be cancelled. 10 minute breaks – time limit (personal care).

### **THEME: Use regulations to define and support breaks**

1. Include a minimum requirement for short breaks, e.g. 2 weeks?
2. Include definition of planning and contingency as well as having a short break.
3. No break should be regulated/legislated for if it's not being directly funded. That would impinge on my freedom and choice, even if the cared for person's replacement cover is (part or full) funded by the Local Authority.

### **THEME: General principles**

1. Make sure carers know their rights.
2. Thinking about things differently.
3. Realism about affordability – creative solutions.
4. Personalisation should not be lost.

## **Topic 2: Adult Carer Support Plan/Young Carer Statement**

The comments in this discussion can be separated into those relating to regulation (11 comments), guidance (6 comments), and implementation (3 comments). Under the theme of 'regulation', the main sub-theme, with 7 comments, is to make the most of existing legislation, regulations and outcome frameworks. Five comments within the 'guidance' theme also relate to this.

### **THEME: Regulation**

#### **Subtheme: Make most of existing regulations and outcome frameworks**

1. Need to highlight needs of carers within existing outcomes frameworks rather than establish a separate one via regulation.
2. Need to avoid setting up a separate system – focus on ensuring Self-Directed Support works for carers.
3. Regulation of specific framework to evaluate is likely to have an adverse effect on practice, which is crucial for successfully implementing an outcomes approach.

#### **Subtheme: Carer views**

1. Have been persuaded that the professionals do not want regulation – I have to respect that they know best?. As a carer I have no experience of working under regulation rather than guidelines.
2. I've no knowledge of national outcomes, (The) group decided a new framework of outcomes for Adult Carer Support Plan/Young Carer Statement wasn't required but I have no idea – for all I know it might be in our (carers') interests to have an additional outcomes framework.

### **THEME: Guidance**

#### **Subtheme: Make most of existing outcome frameworks**

1. Robust guidance is required to support understanding, practice and monitoring of personal outcomes – organisational outcomes – regional outcomes – National Health and Wellbeing Outcomes.
2. Practice – investment in workforce, culture change, ongoing support – and clarification on 'thread' from personal outcomes to organisational to national very important for guidance.

#### **Subtheme: Guidance not regulation**

1. Guidance rather than regulations.
2. As a carer I am conflicted over regulation Vs guidance. Regulation feels rigid and inflexible, guidance feels fluid and holistic, however I wouldn't want people to hide between 'must', 'could' and 'should'.

#### **Other**

1. Good conversations should underpin the plan. Guidance is really important.

### **THEME: Practice and implementation**

1. People carrying out assessments – capability and accountability
2. Look at good practice from areas which have a high number of current carer assessments taking place.
3. Focus needs to be on practice and the achievement of personal outcomes for carers. How these link to a National Framework is an implementation issue, in respect of creating conditions for successful implementation.

### **Topic 3: ACSP/YCS for carers of those who are terminally ill**

9 themes emerge from the 75 notes that were made under this discussion topic:

- Implementation practicalities (14 comments)
- Informing/identifying carers (11 comments)
- Timescales (10 comments)
- Regulation (9 comments)
- Prioritisation (8 comments)
- Principles (3 comments)
- Assessment (4 comments)
- Triggers (4 comments)
- Language (4 comments)

#### **THEME: Implementation practicalities**

##### **Subtheme: Local Authority priorities**

1. Need to look at feasibility for Local Authorities – resources
2. Need each Local Authority to specify their intake system for this group of carers – so nobody gets ‘lost’ and days are lost – meaning timescales not met – should be requirement in regulations/guidance
3. Different for different Local Authorities – how do they prioritise?

##### **Subtheme: Partnership**

1. Apprehension around GPs/Local Authorities/carers centres – what about partnerships – Marie Curie etc.?
2. Carers centres/Macmillan can offer great support – finances/etc.
3. Communication between Palliative Care specific services and generic services.

##### **Subtheme: Procedure**

1. Pilot/test this provision before commencement – see how viable
2. Flow chart – what happens next? Who diagnoses? Work with third sector. What is the process?

#### **THEME: Informing/identifying carers**

1. Things very chaotic for carers – how do they get to know?
2. Possibility of dedicated ACSP/YCS worker?
3. Carer identification is key
4. Rely on health colleagues to identify carers – new diagnosis of terminal illness – who tells their carers they can access support?

#### **THEME: Timescales**

1. Fast-track with Personal Independence Payment, attendance allowance 8 days – structure already there
2. Unrealistic for Local Authorities – holidays etc. – 2 weeks minimum
3. In Glasgow emergency cases allocated in 24 hours – have 21 days to complete care package
4. Timescales – 5 working day not unreasonable
5. What happens if they don't meet targets? – link to monitoring and evaluation

#### **THEME: Regulation**

##### **Subtheme: preference not to regulate**

1. Is the power to regulate about improving prioritisation or improving palliative care?
2. There are equalities issues with regulating for this group but not others (who may have greater needs).

3. Option to not regulate, but have guidance on prioritisation of need, based on impact on carer, rather than condition, or arbitrary life expectancy of cared-for?
4. Is there a need to regulate in this area right now? Palliative and End of Life Care framework to be in.

#### **Subtheme: Link to other systems and processes**

1. Needs to link with other processes – for example, DS1500 form – ensure when this is triggered carers are informed of fast-track ACSP/YCS
2. Support Palliative Care Tool – NHS Lothian – what evidence qualifies?

#### **THEME: Prioritisation**

1. Potential to lose flexibility when prioritisation is forced – can't respond to other priority cases
2. How do we support prioritisation?
3. Cared-for by virtue of diagnosis a priority – referral – are carers automatically high priority at process of referral?

#### **THEME: Principles**

1. Personalised approach
2. No one process – individual approach
3. Support received before crisis

#### **THEME: Assessment**

1. Who does the assessments? What are the questions the carers need to ask? How will they know?
2. Who carries out ACSP/YCS? Respond very quickly

#### **THEME: Triggers**

1. What is the point of trigger? – carers centre/Local Authority
2. Trigger has to happen at Local Authority – LA responsible for not losing cases/back log. Integrated service should help
3. Guidance should make clear communication for procedure for trigger – connecting GPs/carers centres/LAs etc. – make sure no cases get 'lost'

#### **THEME: Language**

1. Distinction between terminal illness and end of life care – what is actual terminology?
2. Influence how it's responded to – health boards may respond negatively to terminology

#### **Other comments in full:**

1. Not a precise science
2. Dual caring role
3. Engage with palliative care nurses working group
4. Make connections with eligibility criteria – instead of regulating just have in-depth guidance
5. What is in place for bereaved carers?
6. What about those on waiting lists?
7. No matter how you do it someone will feel disadvantaged
8. Not sure why we are singling out carers of terminally ill. Should be up there with general prioritisation of the impact of the caring role, e.g. MND, MS

## Topic 4: Monitoring and Evaluation

8 themes emerged from the 76 notes made in this area. The question of what to measure was by far the biggest theme, with people making suggestions ranging from making the most of existing data to suggesting several new measures.

- What to measure (41 comments)
- One size doesn't fit all (7 comments)
- Defining carers (6 comments)
- Action (6 comments)
- Sharing good practice and learning (6 comments)
- Complexity (4 comments)
- Collaboration (3 comments)
- Manageable/proportionate (3 comments)

There was a great deal of diversity in the suggestions that were made about what should be measured. To show this, the lists below are fuller than those above, as there were fewer quotes that were representative of wider views.

### THEME: What to measure

#### Subtheme: Appropriate measures

1. Core set outcome – subsets informed by local need
2. Fewer higher quality measures better – robust and usable
3. Health and Social Care integration – essential that carers are considered as part of the Harry Burns review of indicators. Need a number of different indicators.
4. Important to measure the time taken to complete ACSP/YCS as long delays will impact on the carer
5. Lots of interest in patient experience survey – excellent source for carer outcomes. Felt this was good, as independent from service and asking for carers opinion. Also consistent across the country. Debated whether frequent enough (only every two years) but on balance people thought this was OK.

#### Subtheme: Using existing data

1. Tapping into all existing data sources e.g. academic research – how to make links? Academia and practice
2. Supporting effective accessible use of routine data
3. Many areas noted that at the moment not a lot of good quality data on carers within local authorities, mainly because most of this is only available through the supported person. The Act should change this.
4. Lots of people using the Scotland's Carers publication. People would like to see this developed and the data segmented more e.g. a publication focussing on mental health and caring.

#### Subtheme: Learning from other parts of the UK

1. What has been done in England in terms of monitoring and evaluation – what does this show?
2. Northern Ireland publish quarterly data on carers assessments
3. English 'voices' survey includes questions which relate to carers. Being trialled in NHS Lothian in spring 2017.

<http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcare/system/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>

### **Subtheme: What to analyse**

1. Look at ACSP/YCS compared to all carers in each area in Scotland.
2. Look at deprivation.
3. Look at different routes into service
4. Need to move away from counting things like home care hours and respite weeks and more focus on outcomes.
5. Need both quantitative and qualitative analysis.
6. Comparing hours of care/access to support – improvements in support for high intensity carers
7. Access to support in most deprived quintiles

### **Subtheme: Qualitative data**

1. Integrated Joint Board indicator very high level – but also Health Improvement Scotland/Care Inspectorate work with IJBs – more qualitative data
2. Capture good practice/case studies
3. At basic level number of assessment/output measures – what are the stories behind numbers? – understanding outcomes/reporting personal outcomes
4. Need for mix quantitative/qualitative – interaction different drivers/experiences – understand experiences of different groups of carers

### **Subtheme: measuring the Act's implementation and impact**

1. Understanding contribution/value added of Carers Act
2. Monitoring of local eligibility criteria – consistency
3. Basic measure – increase in identification/assessment

### **THEME: One size doesn't fit all**

1. Measuring success – different for different stakeholders – core and subsets of success measures
2. Better understanding experiences of different groups of carers/segmentation of data e.g. carers for those mental health conditions

### **THEME: Defining carers**

1. Need a definition of unpaid carer. Will there be some sort of publicity campaign setting out what a carer is? Some thought that a checklist would be useful so that people can consider whether they are a carer or not. Who should be identifying carers? Noted that Act is about supporting carers rather than assessing carers.
2. When is a carer a carer? Issues of definitions/identification/awareness
3. Public knowledge of what an unpaid carer is.

[Note: These comments appear to relate to discussions on the day about confidence in the Patient Experience Survey's ability to identify carers.]

### **THEME: Action**

1. Monitoring and evaluation needs to lead onto planning of support.
2. Need to decide how to spend dwindling resources.
3. How do we take action based on evidence?

**THEME: Sharing good practice and learning**

1. Learning from experience/practice elsewhere e.g. Care Act
2. Supporting continuous improvement – understanding what doesn't work
3. What works in different communities/timely sharing of good practice

**THEME: Complexity**

1. Attribution/using contribution analysis
2. What is the baseline and how can we attribute positive change to the Carers (Scotland) Act? How do we track this?

**THEME: Collaboration**

1. Would be good to develop more links with universities and academics. There is a lot of research goes on by PhD students and others which is maybe not being used as much as it could be. Would be good to hold an event with academics to share knowledge. Invite academic onto Evaluation and Monitoring subgroup.
2. Health Improvement Scotland and Care Inspectorate currently carry out joint inspections of local authorities and meet carers groups as part of this.
3. Research outcomes

**THEME: Manageable/proportionate**

1. Awareness of burden of data collection and consistency and reliability – quality
2. Meaningful/doable/comparable
3. Need to also take into account burden of data collection. Fewer robust measures are best.

**Other comments in full**

1. Need for evidence based tools/robust evidence gathering techniques
2. Different spheres for collecting data – making use of these/compare
3. Health literacy (inverse care law)

## **Topic 5: Successful Implementation**

Stakeholder involvement was by far the biggest theme in the notes of this discussion, with 32 comments. As with other discussion topics, how the Act fits with other legislation was another common thread, with eight comments. Seven comments relate to resources and eligibility criteria, and two to the need to review funding systems.

### **THEME: Involvement and conversation**

1. Important not to make the assumption that we 'know all solutions'
2. Important to be open and transparent in conversation with supported people and carers
3. Get leaders of strategic organisations – emotionally connected to issue
4. Know your partners. Plan together, co-produce your plan. Accept there will be 32 variations on a national theme.
5. Full Integrated Joint Board/Local Authority buy-in – their backing of local Carer (Act) Strategy groups is essential, as are dedicated Carers Leads in all 32 too.

### **Subtheme: Carers' voice**

1. Prepare partners at senior level to hear voice of carers – Integrated Joint Boards/Local Authorities – mutual respect
2. Scottish Government could support this – to prepare Local Authorities for conversation – needs to be done if carers want it locally
3. Change perception of carers as contributors, not users of services
4. About ceding 'power' to individuals and feasibility – true outcomes focus driven through Self-Directed Support
5. Need to get senior leaders in Local Authorities/Integrated Joint Boards to start planning now – having conversations with carers/third sector/workforce

### **Subtheme: Timing**

1. Make sure partners are targeted and prioritised at right time
2. Need to accelerate public awareness about legislation and about contribution of people who use support and carers
3. Ensure guidance for Local Authorities, staff, providers, carers and service users is issued well in advance to ensure time for local consultation so that plans and procedures can be established to ensure successful implementation.

### **Subtheme: Congruent message, aspiration and reality**

1. Get one message that secures buy in – all around inescapable shared view
2. Build different messages – for different attitudes
3. Economic message not enough – message is about society we want to be

### **Subtheme: Consensus**

1. We have consensus of aspiration, we don't have consensus in implementation
2. Make sure all partners are engaged

**THEME: Fit with other legislation**

1. Important that it (the Act) dovetails with other legislation and policy e.g. Self-Directed Support and housing
2. Potential of unintended negative consequences of legislation developed in isolation
3. Need a core narrative that connects Carers Act to other policy initiatives
4. Embedding Self-Directed Support is critical

**THEME: Resources and eligibility**

1. Resources and how support is commissioned is key
2. Two pivotal issues to get right: Carer Support Plans and Eligibility Criteria. They must be enabling and similar across all NHS and LA areas.
3. We can't expect to get more results for less Local Authority money.

**THEME: System change - funding**

1. Change system to funding care – increasing investment in care (whole system)
2. Need national conversation about funding model for Health and Social Care

**Other comments in full**

1. Need to promote good practice
2. Must be focus on outcomes – assets
3. Tension between carers' needs and person they care for – how does policy framework deal with that?
4. Supporting carers could mean diverting resources away from cared-for person
5. Leadership
6. Need to have baseline data

## Topic 6: Eligibility Criteria

Six main themes emerge from 57 comments on this topic. The largest theme relates to the principles which should guide the creation and use of eligibility criteria.

- Principles/key issues to consider (18 comments)
- Engaging carers (13 comments)
- Standardisation (8 comments)
- What eligibility criteria should include (7 comments)
- Guidance (6 comments)
- Resources (2 comments)

As with Monitoring and Evaluation, there was such diversity in the suggested principles and criteria that they are listed as fully as possible rather than being illustrated with representative quotes. Equalities are mentioned several times with regard to principles, engaging carers and standardisation.

### THEME: Principles/key issues to consider

1. Preventative approach
2. Early intervention – planning for transition of the cared-for person e.g. moving into education/employment
3. Support as close to point of diagnosis as possible
4. Post diagnostic support
5. Crisis intervention still important
6. All roads cannot lead to social work
7. Train up others e.g. peer support groups
8. Rurality depends on relationship between Local Authority and carers centre
9. Big issues re. rural access
10. Could Self-Directed Support help?
11. Determinants of public health should be included, also should be inclusive of national health and wellbeing
12. Health inequalities – how should these be addressed?
13. Equalities; signatories to human rights
14. Carers as citizens; widest possible rights and how can this be addressed/described in national matters – or elsewhere?
15. Have to be able to deal with fluctuation conditions or crisis situations

### Subtheme: risk

1. Reduce risk of returning again and again for support – prevents crisis
2. Risk reduction – intensity of care, not time spent caring
3. Risk as main criteria – wider impacts such as finances/isolation/having a life outside caring etc. – this would be consistent with determinants of public health; impact of intensity of caring role

### THEME: Engaging carers

1. How to engage with carers effectively
2. Experience of carers in Integrated Joint Boards – lots of consultation but need to think about the lines of communication so information goes to the right places
3. How do you engage with carers who don't know/acknowledge they are carers?
4. Utilise social media to consult, online communities could be tapped into (Macmillan online site/forum as a means to communicating/consulting)
5. Use existing networks and fora to extent that they can be used/want to be used

### **Subtheme: Equalities**

1. Certain groups of people missing from consultation currently – minority groups for example
2. Could look to national bodies to reach out to LGBTI groups, for example
3. In terms of involving carers in defining local eligibility criteria, some easy read info and questions that local areas can use to talk with carers and explore their views on this – it's a confusing area.

### **THEME: Standardisation**

1. Subjectivity in setting local eligibility criteria – need to minimize
2. Deliverable throughout Scotland – rural areas as well as urban – equalities considerations
3. How to assess national standards? – a set date for review should be proposed

### **Subtheme: Sharing practice**

1. Bringing local authorities together to share good practice – coordinated approach is important
2. Local authorities will have to consult with carers and their representatives before setting their local eligibility criteria. What can be done to ensure co-working etc.?
3. Local carers reference group and the Integrated Joint Boards
4. Early pilots, good practice case studies.

### **THEME: What eligibility criteria should include**

1. Risk has to be considered
2. Bear in mind that if carer does not meet eligibility criteria, cared-for person may suffer
3. Criteria has to link to the level of support – but support will be personalised anyway
4. Uses of Self-Directed Support – cases where direct payment seems to assist more than just carers e.g. employing a cleaner
5. Guidance from Scottish Government as to what local eligibility criteria might look like e.g. framework
6. National Carer Organisations framework

### **THEME: Guidance**

1. Good, practical guidance needed for local authorities - health and wellbeing has to be key – if carer is not looked after, costs rise
2. Additional guidance on top of the statutory guidance
3. Guidance from Scottish Government - standard practice for LAs to consult
4. LAs can't start from blank sheet
5. Issuing guidance well in advance of implementation so that Self-Directed Support experience not repeated.

### **THEME: Resources**

1. Resourcing may not be known when local eligibility criteria has to be decided
2. Carers will want to know what kinds of things will be available

**Other comments in full**

1. Early newsletter.
2. Linking all relevant work streams/provisions e.g. ACSP/YCS, eligibility criteria and data collection.
3. Cart before the horse – what is the cart?

## **Breaks from caring**

Guidance could give examples to meet the needs of the individual carer, allowing for flexibility and choice.

Choice and flexibility in guidance.

Carer – caring: choice, break, time out.

Choice is key and flexibility – not one size fits all.

Choice – personalised – short breaks – freedom to decide. Remember 35% of high intensity carers are in poverty.

Framework strong guidance of choice highlighted. Breaks mean different things to different people.

What isn't a break from caring i.e. hospital, work, illness – for guidance, include examples. That is, when someone is ill and person cared for is in respite, so that budget was used and couldn't be cancelled. 10 minute breaks – time limit (personal care).

Rule in rather than rule out what can or cannot be supported.

Broad definition in regulations

Include a minimum requirement for short breaks, e.g. 2 weeks?

Include definition of planning and contingency as well as having a short break.

No break should be regulated/legislated for if it's not being directly funded. That would impinge on my freedom and choice, even if the cared for person's replacement cover is (part or full) funded by the LA.

What helps the carer in their caring role?

Something that works for both person cared for and carer.

An hour a day keeps me happy to care longer. Time for me the carer to do what I want.

Training/education/work – where is the line?

[A break is] Any time spent away from the caring role which allows maximum individual selection use of 'time off'.

A break from the routine.

About the person/carers: could be something like funding for a bicycle for the carer to exercise, getting out.

What should be considered a break? Anything that allows the carer to recharge their batteries. Not time to do things that enable them to care (e.g. housework, paperwork) or employment/education (unless the individual identifies this as their break).

Barriers – cost, resources, lack of skills to support people with specific conditions, lack of provision in rural areas, the carer not feeling they can take time out, not knowing what funding is available.

Make sure carers know their rights.

Thinking about things differently.

Realism about affordability – creative solutions.

Personalisation should not be lost.

## **Adult Carer Support Plan/Young Carer Statement**

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Regulating other than existing legislation – would possibly be more restrictive  
Would not necessarily standardise approach

To regulate on personal outcomes may dilute other frameworks on personal outcomes.

Conversation with structure. Work with existing regulatory structure without adding additional layers.

Need to highlight needs of carers within existing outcomes frameworks rather than establish a separate one via regulation.

Need to avoid setting up a separate system – focus on ensuring SDS works for carers.

Regulation of specific framework to evaluate is likely to have an adverse effect on practice, which is crucial for successfully implementing an outcomes approach.

As a carer I am conflicted over regulation Vs guidance. Regulation feels rigid and inflexible, guidance feels fluid and holistic, however I wouldn't want people to hide between 'must', 'could' and 'should'.

Have been persuaded that the professionals do not want regulation – I have to respect that they know best?. As a carer I have no experience of working under regulation rather than guidelines.

I've no knowledge of national outcomes, (The) group decided a new framework of outcomes for Adult Carer Support Plan/Young Carer Statement wasn't required but I have no idea – for all I know it might be in our (carers') interests to have an additional outcomes framework.

Must – should – could

More about guidance – ensure linked to other agenda  
Guidance rather than regulations.

Guidance – could include links to frameworks

Guidance needs to highlight the range of outcomes frameworks that are out there – signpost people to what's been working well.

Robust guidance is required to support understanding, practice and monitoring of personal outcomes – organisational outcomes – regional outcomes – National Health and Wellbeing Outcomes.

Opportunity to highlight link from personal to organisation and journey

Practice – investment in workforce, culture change, ongoing support – and clarification on 'thread' from personal outcomes to organisational to national very important for guidance.

Good conversations should underpin the plan. Guidance is really important.

People carrying out assessments – capability and accountability

Look at good practice from areas which have a high number of current carer assessments taking place.

Focus needs to be on practice and the achievement of personal outcomes for carers. How these link to a National Framework is an implementation issue, in respect of creating conditions for successful implementation. [GR – i.e. not a guidance issue?]

## **Adult Carer Support Plan/Young Carer Statement for carers of those who are terminally ill**

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A choice to regulate – do we have to regulate? Can it just be in guidance?  
Is the power to regulate about improving prioritisation or improving palliative care?  
There are equalities issues with regulating for this group but not others (who may have greater needs).

Regulating for this group will divert resource away from carers of people not falling into this category but who may have greater needs.

Option to not regulate, but have guidance on prioritisation of need, based on impact on carer, rather than condition, or arbitrary life expectancy of cared-for?

Is there a need to regulate in this area right now? Palliative and EOLC (End of Life Care?) framework to bed in.

Needs to link with other processes – for example, DS1500 form – ensure when this is triggered carers are informed of fast-track ACSP/YCS

SPICT – support palliative care tool – NHS Lothian – what evidence qualifies?

SDS can help with mixed carers

Personalised approach

No one process – individual approach

Support received before crisis

Why is terminal illness prioritised? What about lone carers? Elderly carers? Disabled carers?

Prioritise around impact of care

Chaotic time at diagnosis

Things very chaotic for carers – how do they get to know?

Carers don't know what questions to ask – in no condition to ask

Possibility of dedicated ACSP/YCS worker?

Transitions – crucial. Carers losing out

How can we identify carers?

Whose responsibility is it to ask for support?

Carer not always able – too focussed on caring situation – doesn't think of themselves

Sometimes people just need to know there is support – GP/neighbour/carers centre – not necessarily need to use it

Carer identification is key

Rely on health colleagues to identify carers – new diagnosis of terminal illness – who tells their carers they can access support?

Who does the assessment? – could be third sector

Who does the assessments? What are the questions the carers need to ask? How will they know?

Needs identified through assessment

Who carries out ACSP/YCS? Respond very quickly

What is the point of trigger? – carers centre/LA

Trigger has to happen at LA – LA responsible for not losing cases/back log.

Integrated service should help

Guidance should make clear communication for procedure for trigger – connecting GPs/carers centres/LAs etc. – make sure no cases get ‘lost’  
Who triggers? GPs are overworked

Timescale – 7 days should be target

Fast-track with PIP, attendance allowance 8 days – structure already there

Timescales - 10 days – 7 working days

Unrealistic for LAs – holidays etc. – 2 weeks minimum

SDS/LA – need for fast-track

What happens if the timescales aren’t met?

In Glasgow emergency cases allocated in 24 hours – have 21 days to complete care package

How long is realistic process from preparation to receipt of support?

Timescales – 5 working day not unreasonable

What happens if they don’t meet targets? – link to monitoring and evaluation

Potential to lose flexibility when prioritisation is forced – can’t respond to other priority cases

How do we support prioritisation?

Not everyone needs the same support.

Speed/cost of equipment – hoists/beds etc.

Cared-for by virtue of diagnosis a priority – referral – are carers automatically high priority at process of referral?

What is the policy intent? Ensure those with greatest needs are prioritised? Or to improve palliative care? Would regulating re. 6 month be the best way to achieve this?

Pilot/test this provision before commencement – see how viable

Information and advice service around procedure

Flow chart – what happens next? Who diagnoses? Work with third sector. What is the process?

Need to look at feasibility for LAs – resources

Need each LA to specify their intake system for this group of carers – so nobody gets ‘lost’ and days are lost – meaning timescales not met – should be requirement in regulations/guidance

Different for different LAs – how do they prioritise?

Single point of contact for fast-track priorities in LA – who would refer?

Equality and equity

Concern around being referred to social work – what if social worker on holiday/heavy case load/etc.?

Apprehension around GPs/LAs/carers centres – what about partnerships – Marie Curie etc.?

Carers centres/Macmillan can offer great support – finances/etc.

What is the third sector role?

Support greater from family/friends/third sector than LA

Communication between PC (Palliative Care?) specific services and generic services.

Distinction between terminal illness and end of life care – what is actual terminology?  
Influence how it's responded to – health boards may respond negatively to terminology  
Clarify meanings  
People still not comfortable discussing palliative care

Not a precise science  
Dual caring role  
Engage with palliative care nurses working group  
Make connections with eligibility criteria – instead of regulating just have in-depth guidance  
What is in place for bereaved carers?  
What about those on waiting lists?  
No matter how you do it someone will feel disadvantaged  
Not sure why we are singling out carers of terminally ill. Should be up there with general prioritisation of the impact of the caring role, e.g. MND, MS

## Monitoring and Evaluation

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Need a definition of unpaid carer. Will there be some sort of publicity campaign setting out what a carer is? Some thought that a checklist would be useful so that people can consider whether they are a carer or not. Who should be identifying carers? Noted that Act is about supporting carers rather than assessing carers. When is a carer a carer? Issues of definitions/identification/awareness  
Hidden carers  
Public knowledge of what an unpaid carer is.  
Public awareness.  
Hidden carers.

Measuring success – different for different stakeholders – core and subsets of success measures  
Better understanding experiences of different groups of carers/segmentation of data e.g. carers for those mental health conditions  
Separate out measures of success different groups/stakeholders – recognise there may be conflict  
Different caring roles – how do we collect data that can help us identify trends – good or not – across different care groups?  
Need different approaches for young carers /adult carers / older carers.  
People can have multiple caring roles/experiences – how to understand and measure this?  
Taking account of different experiences/measuring outcomes appropriately e.g. young carers/protected characteristics

Learning from experience/practice elsewhere e.g. Care Act  
Sharing good practice important – how to do this effectively?  
Supporting continuous improvement – understanding what doesn't work  
What works in different communities/timely sharing of good practice  
Share best practice / what works. Need to know what is working and what isn't working.

Understanding contribution/value added of Carers Act  
Linking up different levels of outcome – challenge  
Links to health inequalities and contribution to reducing these  
Not just monitoring and evaluation – also links to planning  
Monitoring of local eligibility criteria – consistency  
Basic measure – increase in identification/assessment

Core set outcome – subsets informed by local need  
Consistency as a measure of success  
Process measures also important – how long? Impact on prevention/timely support  
Role for real-time feedback?  
Care demographics – health/financial circumstances/employment  
Balance quantitative/qualitative  
Frequency data  
Fewer higher quality measures better – robust and usable

The POET outcomes tool developed by Lancaster University was mentioned-  
<http://www.in-control.org.uk/what-we-do/poet-%C2%A9-personal-outcomes-evaluation-tool.aspx>

Health and Social Care integration – essential that carers are considered as part of the Harry Burns review of indicators. Need a number of different indicators.  
Will there be any targets? E.g. a weekly target for completion of carers assessment when caring for someone who is terminally ill  
Important to measure the time taken to complete ACSP/YCS as long delays will impact on the carer  
Lots of interest in patient experience survey – excellent source for carer outcomes. Felt this was good as independent from service and asking for carers opinion. Also consistent across the country. Debated whether frequent enough (only every two years) but on balance people thought this was OK.  
Look at ACSP/YCS compared to all carers in each area in Scotland.  
Look at deprivation.  
Look at different routes into service  
Need to move away from counting things like home care hours and respite weeks and more focus on outcomes.  
Need both quantitative and qualitative analysis.  
Comparing hours of care/access to support – improvements in support for high intensity carers  
Access to support in most deprived quintiles

Tapping into all existing data sources e.g. academic research – how to make links?  
Academia and practice  
Supporting effective accessible use of routine data  
Link to target/indicators review  
How does the achievement of personal outcomes for carers feed into the evaluation of the Act against the framework of National Health and Wellbeing Outcomes?  
Thread between personal/organisational/national outcomes  
Drawing on other data sources/surveys e.g. work on bereavement/patient experiences  
Many areas noted that at the moment not a lot of good quality data on carers within local authorities, mainly because most of this is only available through the supported person. The Act should change this.  
Lots of people using the Scotland's Carers publication. People would like to see this developed and the data segmented more e.g. a publication focussing on mental health and caring.  
What has been done in England in terms of monitoring and evaluation – what does this show?  
Northern Ireland publish quarterly data on carers assessments  
English 'voices' survey includes questions which relate to carers. Being trialled in NHS Lothian in Spring  
2017. <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>

IJB indicator very high level – but also HIS/CI work with IJBs – more qualitative data  
Capture good practice/case studies  
At basic level number of assessment/output measures – what are the stories behind numbers? – understanding outcomes/reporting personal outcomes  
Need for mix quantitative/qualitative – interaction different drivers/experiences – understand experiences of different groups of carers

Attribution/using contribution analysis  
What is the baseline and how can we attribute positive change to the Carers (Scotland) Act? How do we track this?  
Outreach/communication – responsibility and effectiveness – how to measure it?  
Importance of monitoring at different stages of carers journey

Awareness of burden of data collection and consistency and reliability – quality  
Meaningful/doable/comparable  
Need to also take into account burden of data collection. Fewer robust measures are best.

Would be good to develop more links with universities and academics. There is a lot of research goes on by PhD students and others which is maybe not being used as much as it could be. Would be good to hold an event with academics to share knowledge. Invite academic onto Evaluation and Monitoring subgroup. [I mentioned this to Ian Atherton last week when I met him at a conference – Ian peer reviewed the Carers Scotland publication for us)  
Health Improvement Scotland and Care Inspectorate currently carry out joint inspections of local authorities and meet carers groups as part of this.  
Need a way to share good practice, look at good practice case studies.  
Research outcomes

Monitoring and evaluation needs to lead onto planning of support.  
Need to decide how to spend dwindling resources.  
How do we take action based on evidence?  
Reduce health inequalities for carers.  
Use contribution analysis / logic model.  
How to capture carer outcomes / how carers are feeling. Carers centre could use iPads/phone app for instant feedback / real-time solution.

Need for evidence based tools/robust evidence gathering techniques  
Different spheres for collecting data – making use of these/compare  
Health literacy (inverse care law)

## Successful Implementation

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Carers Act doesn't sit in isolation

Important that it dovetails with other legislation and policy e.g. SDS and housing

Capture data we already have – can we revisit the EQIA

Potential of unintended negative consequences of legislation developed in isolation

Rather than reinvent the wheel, can we make the wheel bigger and better?

Need a core narrative that connects Carers Act to other policy initiatives

Embedding SDS is critical

Risks of not joining up journey/pathway of implementation.

Change system to funding care – increasing investment in care (whole system)

Need national conversation about funding model for H&SC

Important not to make the assumption that we 'know all solutions'

Important to be open and transparent in conversation with supported people and carers

LAs need to buy in to this

Strategic leadership required – starting conversation with carers now –

IJBs/LAs/partnerships

Facilitate conversations in partnerships

Get leaders of strategic organisations – emotionally connected to issue

Early communication – among all partners

Accelerate communication about the Act to wider groups – third sector, private sector (care home).

Know your partners. Plan together, co-produce your plan. Accept there will be 32 variations on a national theme.

Full IJB/LA buy-in – their backing of local Carer (Act) Strategy groups is essential, as are dedicated Carers Leads in all 32 too.

We have consensus of aspiration, we don't have consensus in implementation

Need to get them to buy in to emotional/moral message

Make sure all partners are engaged

Congruent message, aspiration and reality (example of SDS)

Message needs to be rooted in reality and practice

Get one message that secures buy in – all around inescapable shared view

Build different messages – for different attitudes

Economic message not enough – message is about society we want to be

Prepare partners at senior level to hear voice of carers – IJBs/LAs – mutual respect  
SG could support this – to prepare LAs for conversation – needs to be done if carers want it locally

Carers themselves to challenge/push

Change perception of carers as contributors, not users of services

About ceding 'power' to individuals and feasibility – true outcomes focus driven through SDS

Leadership - converse with carers now and consistent quality to process systems, experiences

Start conversations with carers now – locally support that  
Need to get senior leaders in LAs/IJBs to start planning now – having conversations with carers/third sector/workforce  
Gloves on or gloves off, communication is exhausting if people aren't prepared for hearing the voice of carers.

Make sure partners are targeted and prioritised at right time  
Need to accelerate public awareness about legislation and about contribution of people who use support and carers  
Austerity a difficult environment for positive change  
Timeframe of messaging national/local needs to be enabling  
Strategies at local level now... eligibility criteria – agree  
Ensure guidance for LAs, staff, providers, carers and service users is issued well in advance to ensure time for local consultation so that plans and procedures can be established to ensure successful implementation.

Resources and how support is commissioned is key  
Eligibility criteria is key – need to inform conversations  
Pivotal to successful implementation – eligibility criteria/ACSP – important to have consistent practice across country  
For successful implementation, there need to be good, inclusive eligibility criteria across the country.  
Two pivotal issues to get right: Carer Support Plans and Eligibility Criteria. They must be enabling and similar across all NHS and LA areas.  
We can't expect to get more results for less Local Authority money.  
Assessment not to be a tick box.

Need to promote good practice  
Must be focus on outcomes – assets  
Tension between carers needs and person they care for – how does policy framework deal with that?  
Supporting carers could mean diverting resources away from cared-for person  
The better and more consistent the Carer Support Plan, the better the implementation and outcomes will be.  
Leadership  
Need to have baseline data

## Eligibility Criteria

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Subjectivity in setting local eligibility criteria – need to minimize  
Deliverable throughout Scotland – rural areas as well as urban – equalities  
considerations  
How to assess national standards? – a set date for review should be proposed

Bringing local authorities together to share good practice – coordinated approach is  
important

Local authorities will have to consult with carers and their representatives before  
setting their local eligibility criteria. What can be done to ensure co-working etc.?:

Networking is important

Local carers reference group and the IJBs

Early pilots, good practice case studies.

Reduce risk of returning again and again for support – prevents crisis

Risk reduction – intensity of care, not time spent caring

Risk as main criteria – wider impacts such as finances/isolation/having a life outside  
caring etc. – this would be consistent with determinants of public health; impact of  
intensity of caring role

Preventative approach

Early intervention – planning for transition of the cared-for person e.g. moving into  
education/employment

Support as close to point of diagnosis as possible

Post diagnostic support

Crisis intervention still important

‘All roads cannot lead to social work’

Train up others e.g. peer support groups

Rurality depends on relationship between La and carers centre

Big issues re. rural access

Could SDS help?

Determinants of public health should be included, also should be inclusive of national  
health and wellbeing

Health inequalities – how should these be addressed?

Equalities; signatories to human rights

Carers as citizens; widest possible rights and how can this be addressed/described  
in national matters – or elsewhere?

Have to be able to deal with fluctuation conditions or crisis situations

Eligibility criteria needs to be realistic

Risk has to be considered

Bear in mind that if carer does not meet eligibility criteria, cared-for person may  
suffer

Criteria has to link to the level of support – but support will be personalised anyway

Uses of SDS – cases where direct payment seems to assist more than just carers  
e.g. employing a cleaner

Guidance from SG as to what local eligibility criteria might look like e.g. framework  
NCO framework

Good, practical guidance needed for local authorities - health and wellbeing has to  
be key – if carer is not looked after, costs rise

Guidance from SG

Additional guidance on top of the statutory guidance

Guidance from SG - standard practice for LAs to consult

LAs can't start from blank sheet

Issuing guidance well in advance of implementation so that SDS experience not repeated.

Resourcing may not be known when local eligibility criteria has to be decided

Carers will want to know what kinds of things will be available

How to engage with carers effectively

Experience of carers in IJBs – lots of consultation but need to think about the lines of communication so information goes to the right places

How do you engage with carers who don't know/acknowledge they are carers?

Need to find alternative methods to get to these carers – go to carers where they are

Utilise social media to consult, online communities could be tapped into (Macmillan online site/forum as a means to communicating/consulting)

SG need better social media presence which can be used

Variety of approaches is required – one size does not fit all

Use existing networks and fora to extent that they can be used/want to be used

Identification of carers important – cultural issues – need to change perceptions

Certain groups of people missing from consultation currently – minority groups for example

Could look to national bodies to reach out to LGBTI groups, for example

LAs/H&SCPs need to be proactive in this

In terms of involving carers in defining local eligibility criteria, some easy read info and questions that local areas can use to talk with carers and explore their views on this – it's a confusing area.

Early newsletter.

Linking all relevant workstreams/provisions e.g. ACSP/YCS, eligibility criteria and data collection.

Cart before the horse – what is the cart?