

**Carers Act: Data collection and monitoring
Second meeting of short-life working group**

Thursday 21st July 2016

Room B14, Glasgow City Chambers

Attending: Mike Brown - Social Work Scotland (chair)
Fred Beckett - Glasgow City Council
Philip Brown - City of Edinburgh Council
Susan Webster - East Dunbartonshire Council
Julie Young - The Dixon Community
Fiona McCulloch - Greater Glasgow and Clyde
Heather Noller - Carers Trust
Ben Hall - Shared Care Scotland
Ann Cummings - Glasgow City Council
Margaret Curley - Glasgow
Julie Rintoul - Health and Social Care Analysis, SG
Lynn Lavery - Carers Policy, SG
Alexandra Rosenberg - Health and Social Care Analysis, SG
Stewart McIntosh - ScotXed, SG
Martin Devine - Health and Social Care Analysis, SG

Apologies: Fraser Mitchell - Fife Council
Lynn Gallacher - Borders Carers Centre
Don Williamson - Shared Care Scotland
John McLean - ScotXed, SG

Demonstration of Glasgow's system for supporting carers

Fred and Julie Y gave a presentation on the system used in Glasgow to identify and support carers.

- this uses a whole system approach, with the various organisations involved working together
- all organisations involved record the same information to the same dataset using the same system
- the focus is on enabling and empowering carers, not just on addressing their needs

All carers are offered an assessment - this is the same assessment for all, with a flexible approach used to make the assessment appropriate and proportionate for each individual carer's needs.

The emphasis is on preventative action and early intervention, with care being seen as part of the wider system - where there is a carer, there will be someone who requires care because of a long-term condition. Information on people diagnosed

with a long-term condition can be used to predict where carers are most likely to be, and will give an indication of potential future need (e.g. where the long-term condition is likely to get worse, meaning that the level of care required will increase). There is usually a strong link between the cared-for person's journey and the carer's journey.

The data collected on the system includes information on both the carer and the cared-for person, and includes:

- cared-for person diagnosis information
- hospital/medical information on both the carer and cared-for person - this can be tracked over time to analyse the impact of the support provided
- GP visit records
- the source of the referral - this allows analysis of the effectiveness of the system (e.g. by looking at the relative balance of referrals by source over time)

Providing support at the earliest point that it is needed is a more efficient use of limited resources than providing help/support only at the point of crisis - crisis intervention is expensive! In addition, finding the people who need support sooner means that there is better knowledge of demand, so less worry over the potential for large numbers of unknown carers who may come forward requiring assessment or support.

All assessments carried out from all sources are entered on a single system and retained for potential future reference.

Action: How do voluntary organisations access the system? (Fred)

The assessment concentrates on outcomes - looking at the needs of the carer and if these have been met, with less emphasis on what help/support has been provided. This was a significant change to 'traditional' ways of providing support to carers, so training was required for all staff involved. A change of mindset has also been required - from 'rescuers' (getting someone out of a crisis in the short term) to 'supporters' (providing appropriate help and support for longer-term needs as well as the short term), and from asking 'What does the carer need?' to 'What will make a difference to the carer?'.

There has been a move away from concentrating on simple numbers (e.g. comparing the number of carers in different areas) to a focus on improving outcomes for carers. Services are the same across the area, so users will receive a more consistent level of service if they move, and funding for services is for the whole area, not by local area - removes the need for areas to compete for a bigger slice of the overall funding. There has also been a shift away from highlighting poor

performance to highlighting (and rewarding) good performance - this helps to motivate the people and organisations involved to do a good job.

Action: Local authorities to share with SG the fields and field descriptions that are used to collect data on carers in their systems.

Minutes/actions

Mike went through the minutes and actions from the first meeting. This initiated a discussion of outcomes - how to measure these, and if that should be a part of the work of this SLWG.

Lynn set out the proposed SG approach - the data collection to be set up as a result of the SLWG will concentrate on inputs and outputs, with initial (baseline) data for the period before implementation being compared to post-implementation data, with outcomes being measured/analysed in research and evaluation further down the line.

Several questions came out of the discussion:

- What is meant by 'outcomes' in this context?
- What information can be collected on these outcomes 1) now? 2) as part of the proposed data collection?
- Is it possible to collect this type of data? (If different LAs/organisations have different processes, comparability becomes an issue - any data captured/collected needs to be useful and meaningful.)
- Will collecting data on outcomes influence the assessment process? (e.g. if the data collected is used to produce comparisons between areas)

Action: Outcomes to be included in the agenda for the next meeting.

Data specification

The rest of the meeting was made up of a discussion of the draft data specification and the criteria to be used for inclusion in the data.

General points: A balance between the data that we want (or would like to have) and what we need is required - as the data spec is to go out for consultation, the thinking among the group was that we should tend towards asking for the data that we want, then see if local authorities are able to provide this.

The data collection should cover both pre- and post-implementation of the Carers Act (currently scheduled for 1/4/2018), i.e. be appropriate and relevant both now and in the future.

The data spec should use the 'new' terminology where possible - for example, refer to ACSP and YCS rather than 'assessment'. Some local authorities, however, will take longer to implement the change to the new system, so we need to be aware of the transition between the two.

Unique ID numbers: These are an important part of the data collection - in particular:

- all records that refer to a given person should have the same ID, irrespective of the status of that person (carer or cared-for person)
- the same ID should be used for that person over time (i.e. the ID allocated to a person in the 2016 data collection should be used to refer to that person in 2017, 2018 and so on).
- if a person appears in other data collections, the same ID should be used - this will make it easier to link datasets

Encrypted CHI would be ideal for this in the longer term, but it is not currently being used/collected by all local authorities (although use of CHI is increasing).

Carer data: It is important to clearly define who should be included in the data collection.

The initial thought was to include everyone who has been offered or has requested an ACSP/YCS. There are a few issues with this, however - where someone is receiving support without having gone through an assessment, or where another form of assessment has been used.

A wider definition (e.g. include all carers, not just those who have been assessed) would capture more people and give a more complete dataset, but it is likely that it would be more difficult for local authorities to collect and provide this data.

The exact definition of who should be included will depend on the regulations that will go alongside the Act - these are still to be finalised. An initial draft definition is:

Data should be provided for anyone who, during the reporting period

- has had, been offered or requested an assessment of their needs as a carer
- has received at least one of the following services (list of 'qualifying' services to be included here)
- provide care for a cared-for person who has received respite care

Possible issue: Some carers will provide care over a period of several years, and it is likely that there will be years where there is no need to assess/review or change the support that they receive. If we define 'carer' as above, based on what has happened during the reporting period, these people will potentially be missed out of the data collection.

Reviews of assessments should be annual (and may be more frequent, e.g. Glasgow aim for a review every 3 months), but this does not always happen - this suggests that 'inactive' carers should be included in the data collection.

How easy is it for LAs (or other organisations that provide assessment/support for carers)) to collect information on people who have previously been assessed and are known to be carers, but have not received a review in the reporting period? (A question to be included in the consultation?)

If people who have received one of a list of services are to be included in the data collection, what should be included on that list? An extreme example - a person who has received information and advice only.

A definition of 'review' will need to be included in the data spec - this could potentially take several different forms (e.g. a formal process, a face-to-face meeting between the carer and a support worker, a telephone conversation).

Personal data fields: Including personal data like name in the collection is not essential, but will potentially be useful for matching with other datasets in future. Any personal data collected will be encrypted, similar to other SG Health and Care surveys/data collections.

Ethnicity: The proposed ethnicity variable will collect data at a relatively high level, and is consistent with the Census data.

Care hours: While some local authorities (e.g. Glasgow) do not collect this, and the number of hours of care provided by a carer will vary from week to week in many cases, this data is used by Shared Care Scotland and the Carers Trust, and by SG for comparison with carers data from the Census and SG surveys. This is also useful for checking if the threshold for Carer's Allowance has been reached (35 hours of care per week).

The proposed approach was to retain this question in the collection, and ask for feedback from local authorities and other data providers in the consultation.

It was also suggested that would be useful to ask for the length of time the carer had been caring. This would be helpful in measuring the outcome that more carers are identified at an early stage in their caring role so that they are supported.

Action: Martin to add new question on "length of time the carer has been caring"

Health condition: The list in the data spec was taken from the Social Care Survey, and is at a relatively high level. At least some local authorities (e.g. Glasgow, East Dunbartonshire) collect data on health conditions (of both the carer and cared-for person) in more detail - down to individual conditions, particularly for conditions that would result in care being required.

One reason for Glasgow collecting this information is to build relationships with and provide evidence of the impact of support to carers to their NHS colleagues.

Action: Glasgow (Fred) and East Dunbartonshire (Susan) to provide the lists of health conditions available on their respective systems to SG.

Type of care: More work is required on this variable - need to define the data to be collected and the options available. One possibility is to use the categories used to for Direct Payments in the Social Care Survey:

- Health Care
- Domestic Tasks
- Housing Support
- Social/Educational/Recreational
- Equipment and Temporary Adaptions
- Short Breaks (Respite)
- Meals
- Other

(taken from p36-37 of the Social Care Survey guidance -

<http://www.gov.scot/Topics/Statistics/Browse/Health/SocialCareSurvey/SCguid2015>)

Amount of care that the carer is willing to provide: This is currently in the 'Carer' section of the data spec - likely to be a better fit in the 'Assessment' section.

What will this be used for? To identify cases where a person is providing more care than they are willing to - this would be an 'identified need'.

There is a difference between the amount of care that a carer is able to provide, and the amount of care that they are willing to provide, so it is worthwhile to have separate questions in the data collection to cover both aspects. In particular, there should not be an assumption that someone who is currently providing care is willing to continue to provide care.

Data on the cared-for person: It is likely that the cared-for person will not be involved with the ACSP/YCS, which raises the issue of potentially being required to collect data about the cared-for person when they are not aware of this - this raises potential problems around permissions, confidentiality, data security, etc.

Source of referral: This should be added to the data spec - the person/organisation who offered/initiated the carer assessment process (e.g. carer, social worker, GP, nurse, etc.).

Action: LAs to provide SG with the list of potential options that they use on their system for the source of an assessment.

Assessment offered/requested/declined/etc.: It was felt that the questions covering this part of the data could be improved:

- additional or different options for the 'assessment requested or offered' question - self-identified, referred, etc.
- include the reason for a request for assessment being declined in the dataset
- include a free text field (or Other category with free text) for an explanation of why an assessment has not been completed

Eligibility: The spec currently has one question on eligibility (Is the carer eligible for support? Yes/No), which the group felt was not sufficient - in particular, data on eligibility bands and thresholds should be collected.

The Carers Act specifies that eligibility criteria are determined locally (with local authorities able to set both bands and threshold), so there are potentially issues around consistency between LAs. Should there be a (separate) survey to ask LAs about the eligibility criteria that they use?

It is likely that eligibility criteria will change over time (e.g. higher/increased thresholds as a result of reducing resources) - this is something that would be useful to keep track of.

Action: Lynn to check the exact position on local/national eligibility criteria, and report back to the group.

Support needs/provision: The questions as they are currently specified in the data spec ask for the needs of the carer and the services that the local authority will provide. Should there be an additional question on services/support that the carer is receiving from other sources?

The list of options for support in the two questions could be changed to be consistent with the six core services which are used in Glasgow:

- Information and advice
- Emotional support
- Money matters
- Short breaks

- Training
- 'Having a voice'

Should data on the amount of support received be included in the data collection?

There is a need to monitor demand for carer services following the implementation of the Act - while the Financial Memorandum estimates the cost, it is recognised that there is a lot of uncertainty around these estimates, and this data collection is one potential source of data that could be used.

Mike pointed out that the current data specification does not include any cost information or data - given the uncertainty over future costs relating to the Act, it would potentially be very useful to collect data on the cost of providing support to carers.

Inputs/outputs or outcomes/impact: The data collection, as currently specified, concentrates on the inputs and outputs involved with providing support for carers - there is, however, an argument to be made for concentrating on the impact of the support provided and the outcomes for carers.

The ideal situation would be to collect data on inputs/outputs and outcomes, and use the data to show how these can be linked together.

Structure of data: Mike felt that the data spec did not explain the structure of the data well enough, and suggested that a section should be added to the spec to give a better explanation.

Action: Martin to add a section explaining how the data will be structured to the data spec.

Action: Martin/Julie to update the draft data spec to reflect the issues and questions raised at the meeting, and circulate an updated draft at least one week in advance of the next meeting of the group.

Next meeting

24th August, 10am - 12 noon

Room GN.07, St. Andrew's House, Edinburgh