

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

Wednesday 29th June 2016

Meeting Room 1, 2WR, St. Andrew's House, Edinburgh

Attending: Mike Brown - Social Work Scotland (chair)
John McLean - ScotXed, SG
Julie Rintoul - Health and Social Care Analysis, SG
Lynn Lavery - Carers Policy, SG
Fraser Mitchell - Fife Council
Julie Young - The Dixon Community
Fred Beckett - Glasgow City Council
Philip Brown - City of Edinburgh Council
Lynn Gallacher - Borders Carers
Fiona McCulloch - Greater Glasgow and Clyde Health Board
Donna Hamilton - Falkirk Council
Martin Devine - Health and Social Care Analysis, SG

Apologies: Susan Webster, East Dunbartonshire

Background

Julie R provided background information to the group:

- a summary of the current position on data relating to carers currently being collected and published, and what may be required in future
- the Finance Advisory Group for the Carers Act – work on the funding requirements
- the need for baseline data to be able to assess the impact of the Carers Act once it comes into force – outcomes for carers, level of demand for assessment and support plans (ACSP/YCS), level of need for all types of support, including respite care.
- a potential timetable for implementing this data collection from 1 January 2017

Membership

It was suggested that a representative from one of the National Carers Organisations would be a useful addition to the group.

Action: Lynn to contact NCOs to ask if they would like to propose someone to be on group.

General Discussion – data collection

This led into a discussion of the data available and potential issues with collecting the data:

- Need to think about what the data will be used for, what is needed for local use and what is needed for national monitoring.
- Local Authorities all have different assessment processes and will be important to define key information required nationally. The Act does specify certain things that must be included in the ACSP/YCS, so there is likely to be some common ground.
- Once we have defined the data required, will then need to consider who will be providing the data - local authorities, carers centres, wider health services?
- If collecting data on ACSP/YCS then important to ask who was offered an assessment as many people may decline and only collecting completed assessments may miss a large proportion of activity taking place.
- Eligibility criteria are set locally, which may add another potential source of inconsistency.

Data collected by local authorities

Glasgow: Have a system that records information on carers and allows carers to be identified at an early stage which has resulted in early intervention and preventative work leading to potential savings. The group expressed interest in seeing a demonstration of the Glasgow system and it was agreed to try and arrange this to coincide with the next meeting. It would also be useful to see any documentation about what information was collected.

Action: Fred/Julie along with Ann Cummings to look into arrangements for a demonstration of the system used in Glasgow to coincide with the next meeting of the group on 21st July at 2pm. (This may involve moving the location of the meeting to Commonwealth House, Glasgow.)

Fred to circulate any relevant documentation on how and what information on carers is collected in Glasgow.

Edinburgh: Able to identify carers from different sources, but do not have 'joined-up systems'. Their recording of eligibility for support has improved since the introduction of personalisation.

Systems in Edinburgh and Falkirk both have a 'carer' field in an individual's social work record, so the carers that they know about are a subset of those people known to social work services.

Fife: Personal Outcomes Approach for service users has been introduced and is collected on SWIFT/AIS. This will include some basic information on Carer Support Plans offered and accepted

What type of support do carers receive?

Throughout the discussion the following support was identified:

- information and advice, including financial advice
- support through carers centre
- training
- signposting (allowing carers to self-identify as carers)
- short breaks/respite
- equipment and adaptations

Outcomes for carers

It was felt that measuring the effect of support provided to carers is more important than recording exactly what support is provided. However it was also recognised that monitoring the additional eligible requirements for support to carers as a result of the new Act, and its cost, would also require information on service volumes and expenditure.

The current thinking of SG analysts is that the new data collection will be used to measure inputs/outputs on ACSP/YCS and the support for carers that results from this. The current main national source of data on outcomes for carers is the SG [Health and Care Experience Survey](#) which is run every two years. The group asked for more information on the Health and Care Experience Survey and also asked if development on measuring outcomes for carers was being undertaken or planned by other groups.

***Action:** Martin to produce brief paper for next meeting on the relevant questions in the Health and Care Experience Survey.*

Action: Lynn/Julie to check position re other work on developing outcomes.

Point raised that there is some duplication between Young Carer Statement and Child's Plan.

***Action:** Martin to find out if there are any national data collections asking for information about Child plans.*

Data issues to be addressed

Several relevant questions raised:

- How are carers identified – by the local authority, carers centres, NHS, GPs, voluntary sector?
- What data items are most important/useful? (for SG? for LAs? for HBs? for carers?)
- Who is carer caring for? (Including data on the cared-for person will give useful context for the carer's situation)

- Why does the cared-for person require care? (Could be used as a proxy for amount of care provided, where this could not be captured directly?)
- Who is making the referral for assessment? (e.g. hospital, GP, self, third sector, friend/family/neighbour)
- What is the purpose of collecting the data? What is the data going to be used for? (to assess impact of Act, to provide evidence of areas where service could be improved (e.g. where NHS staff are not identifying/referring carers))
- What data/information would be useful to the NHS? (e.g. to improve services)
- How do LAs capture/record what is being done? (particularly if referrals for assessment are being made by other organisations, e.g. NHS, third sector)
- How do you show the impact of preventative measures/early intervention?
- What organisations should be included in the data collection? (anyone will be referring people for assessment?)
- Respondent burden of providing data

It would be useful to be able to differentiate between initial assessments and reviews, particularly as there is likely to be more variation in the amount of work involved in a review (from minor or no changes in carer's situation to a full reassessment).

In addition to statistics produced from this data collection, the impact of the Act will also be assessed through other research studies and evaluation.

Integrating this data collection with the Social Care Survey is a potential future option, and has the advantage of making it easier to link carers to the relevant cared-for persons.

Some groups thought to be less likely to identify as carers than others - e.g. where a person has mental health or addiction issues.

[Note: following meeting have checked the Inpatient bed census which focusses on Learning Disability, Mental Health and Addictions. This asks whether each patient has a carer so could be a source to explore further]

Action: *Julie and Martin will circulate a draft data specification for discussion at the next meeting.*

Data linkage

Other data sources were mentioned during the course of the meeting such as Social Care Survey and Delayed Discharges Census. If data is collected at an individual level for carers then this will provide opportunity to link with other data sources.

Next meeting

Currently set for 2-4pm on 21st July 2016 in Glasgow.