Main headlines from the Networked Data Lab analytics on unpaid carers

Background

Network Data Lab in Leeds has conducted research to establish gaps in the knowledge of the Leeds population regarding the needs of unpaid carers and the utilisation of services by unpaid carers. This paper pulls together the main headlines of 2 pieces of analytics.

1. Registered carers
2. Carers assessment pathway

Original Questions to look at:

1. Health outcomes of unpaid carers
2. Impact of carers accessing council services
3. How are support services being used?
4. Are all carers aware of services and receiving them?

What outcomes are we wanting to achieve from this project?

We are wanting to understand the unmet needs for unpaid carers: Building on intelligence and better understanding the support needed. The start of that process is to get people registered.

What did we find out about identifying registered carers using GP data?

The headlines

- 65.000 unpaid carers in Leeds (source 2021 census)
- Needs of unpaid carers are complex with 83% reporting a negative impact of caring on their physical health – 87% impact on their mental health
- Out of 65K only 19K have informed their GP – rise in 2020 – covid
- More females than males registered
- No trend observed with deprivation, people who live in the most deprived areas are roughly as likely to tell their GP they are carers as those who live in less deprived areas

- People in deprived areas are more likely to have poorer outcomes so we assume that people from these areas would be more likely to care for someone but this is not seen in the registration numbers -potentially pointing to a lack of registration among areas of higher deprivation.
- Carers who speak English as first language is 85%
- Non English is 5% - does this mean that non English are not registering and making themselves known?
- We know that most carer registrations come from older age groups – typical persona white British retired woman

Pre-covid
- People from less deprived areas seem to register in the autumn – driven by the flu jab
- Base number increases seasonally

Discussion and conclusion
- This work has looked at registration rates by GP practices and secondary care interactions
- Registered carer rates have been increasing between 2016 – 2021 with a sharp increase in 2020 linked to the pandemic
- Carers do not look after their own health. Early data analysis shows that unpaid carers could have more significant health characteristics to people who are 10 – 15 years older than themselves. This information was also reflected in conversations with the task and finish group
- Registration rates are unequal across demographics – men around 40 – 50% less likely than women
- Younger people (18-39) 10-20 times less likely to register than retirement age
- Non-english speaker 10-40% less likely to register than English speakers
- Chinese and Black, Black British less likely than white British to register
- Indian and Pakistani are more likely than white British to register as carers
- Retired British women are more likely to register as carers as opposed to
  - Non English speakers
  - Men
  - Chinese and African
  - People who live in deprived areas
  - Working age across the range age

Registration Dates
- Spikes in registration during Autumn vaccinations and then during covid
- Retirement age has a large increase in registrations
- Beginning of pandemic whilst working age patients had increased registrations and the onset of the vaccination programme
- Clear trend that during periods of increased call for carer registration the numbers increased greatly

- These drives are successful– these drives seem more effective in areas of lower deprivation where interactions with GPs are more routine – should more comms or engagement benefit these drives?

Health Needs
- Carers tend to have poorer health outcomes from non-carers – they put off their health needs
- Carers have a similar rate to non-carer for elective care but have a higher rate of attendance in A&E in most age bands. More women are attending A&E

NDL Adult Social Care Data – Support for unpaid carers

It should be noted that the interpretation of analysis was limited by small numbers of carers and cannot be considered representative of the carer population in Leeds.

The 2021 Census identified approximately 65,000 unpaid carers in Leeds. Services such as home care, sitting services and direct payments can be provided for unpaid carers through assessment by Adult Social Care (ASC). Between 1/1/2016 and 31/12/2021 there were 1,977 referrals for a carer assessment from a maximum of 1,361 known individuals.

How it currently works

Typically, unpaid carers looking to access support contact the social services in Leeds (the local authority – LA) and can be signposted to sources of community services (mainly Carers Leeds) or, if they are eligible, referred for a carers assessment. A joint carers assessment can also provide indirect support (such as respite) as part of a wider package of care for an adult social care service user. These contacts are recorded through the CIS case management system and flow into the Leeds Data Model (LDM).

Analysis presented here shows;
1) Only 2.1% of carers in Leeds have been assessed for support through the Local Authority (LA).

2) 67% percent of carers are female, compared to 31% male (with 2% unspecified gender).

3) On average, 225 carer assessments take place each year.

4) 38% of those carers who have a carer assessment receive a support plan to provide services.

5) It is impossible to determine the total number of carers seeking support from the data available. Only carers referred for a carer assessment were included here.

Key analysis

There was a wide representation of unpaid carers aged 18 to 99 from across Leeds. Females, between the age of 50-59, living in the most deprived areas (IMD decile 1) typically had the most carers assessments.

Gender and age

Between 2016 and 2021 Leeds had an average of 320,896 (51.5%) females and 301,769 (48.5%) males over 18. In contrast, 68% of carers were female and 31% were male. This imbalance was greatest in the lowest age band (18-29) and generally reduced as age increased.

Demographics and age

Younger age bands were dominated by carers from the most deprived areas (IMD decile 1). There was an increasing proportion of carers from more affluent areas as their age increased. This is also observed in the underlying population, but to a lesser extent.

The patterns identified above were consistent across each year of the study, but yearly breakdowns suffered from low sample sizes. Similarly, data was stated as percentage of the population with caring responsibilities, but again, it was difficult to draw conclusions with such low numbers.

Looking at the pathway

The pathway from carer assessment to service provision is variable depending on carer circumstances. Multiple conversations may occur before a support plan is issued and decisions are not well documented. Poor understanding of assessment pathways makes it difficult to estimate time from referral to service provision.

Inequities in service provision

Between 2016 and 2021, 533 (39.5%) of 1,350 carers who were referred for a carers assessment received support. The criterion for carer support is independent of age, gender, financial status and other demographic information and this is consistent with the analysis conducted here. However, considering such small numbers of overall referrals, it is surprising that approximately 60% of unpaid carers do not meet the criteria for support.

Ultimately, only 0.82% of the estimated carers, or 0.086% of the population in Leeds receive carer support.

Unpaid Carers Task & Finish Group Feedback

Key themes that mattered to the group from the analysis

- Low numbers of people registering with their GP – Do we need a consistent offer of benefits from GP practices?

- Agreed GP should be the focal point of registering as 95% of carers are registered with a GP: there are health benefits for registering, i.e., early vaccination and signposting.
- Un-paid carers don't look after their own health needs – Do GPs needs to offer an annual health check?
- Low number of people being referred for a carers assessment
- Low numbers of people being successful in getting a carers assessment
- Confusion over the system – if English speaking people are confused where does that leave people who English is not their first language. – work is being done to raise awareness with GP practices, but do we need to raise awareness with people on the street?
- People need a carers road map
- Make sure interpreters are used to explain to carers the road map (this could be translated into most popular languages)
- More awareness around carers assessment – do all GP practices have the same processes of informing people of the carers assessment and details to contact carers Leeds once they register?