An enabling infrastructure for the social care sector

By introducing person-centred data infrastructure, the social care sector can directly improve the lives of over 230,000 Scots[1] who access social care, the wellbeing of their loved ones and those who provide support to them, whilst increasing the efficiency of service delivery overall. In Scotland and beyond there is a high-level policy goal of person-centred, self-directed, and participatory approaches to public services. The way we manage our data has to match up to the way we approach our activities, this is very pertinent to the social care sector. There is a way to overcome the friction, effort, risk, and cost of fragmented systems in social care, one that is being recognised by independent review:

"Scotland needs to shift its attitude towards technology and data sharing to improve people's experience of social care … Technology is not a replacement for support provided by another person but it can play a much bigger role in improving the lives of people who use social care services and supports. It can also help with people's ownership of their care and support, particularly when people "own" their own data or information that is about them and share it with the people who support them" ~ Scottish Government, 'Independent Review of Adult Social Care'

Below, we have outlined four potential benefits from person-centred data management, which Mydex CIC's platform services already provide in Scotland:

Interoperability

Social care is provided by various organisations and there is often a significant need to communicate and coordinate between many of them about a single individual benefitting from care, depending on the type of care being provided - whether its statutory health or justice bodies, advice services, or other private sector care organisations. From the perspective of people using the services and those closest to them, nobody wants or needs to see demarcation lines between sectors, organisations, policy or departmental functions. They want a truly holistic approach that fully understands their particular needs and circumstances, and responds to their particular situation sensitively and appropriately. A significant barrier to achieving this is the sharing of personal information, specifically, the lack of infrastructure that enables this.

Such an infrastructure cannot logically, legally, or operationally be provided by any one particular care provider. It is not possible or desirable for a GP surgery to hold or share data collected by a care home or social services, or vice versa. What is needed is an extra level of data sharing - an additional 'layer' of data sharing infrastructure - that helps each separate agency join the dots, sharing what information needs to be shared safely, seamlessly and efficiently when needed.

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[1] Based on the most recently available official data

Personalisation

Detailed information and nuanced, intimate knowledge of an individual is incredibly important to providing good care. A personal assistant knowing whether or not glasses are for reading or for distance, or whether the person they're assisting prefers to drink a cup of tea before or after breakfast would make all the difference to the quality of support people in social care would receive. It's difficult for busy frontline staff to have that sort of information on hand and difficult to recall. Were person-centred data the standard architecture, this level of detail would just exist, placed in people's Personal Data Stores by themselves or those that know them best. Organisation-centric models of data management will never achieve this intimacy of detail, because they naturally lead to information being managed to serve the purposes of the organisation rather than the individual and create such a level of overhead in collecting that data and sharing it as to thoroughly disincentivise true personalisation.

Control

The Care Act 2014 understands *'control by the individual over their day-to-day life (including over care and support provided and the way they are provided)'* as an important aspect of wellbeing. This must include control by the individual over their data too: what information about them is created, how it is shared, and to whom it is sent and why. Whether the ability to make decisions about that data lie with the individual themselves or those nominated to control their affairs on their behalf, this aspect of wellbeing would be increased and in many ways assured by including control of their personal data.

Consistent fidelity over a lifetime

Everybody accessing social care services have or are about to create a history. Their lives and needs change. All of the above could be maintained from cradle to grave by the adoption of a person-centred data infrastructure. Each individual would have a rich record of everything about them, under their control, updated whenever it needs to be either by them or the social care providers that need and alter that information to provide services to them. This becomes especially pertinent to cases of people accessing support with cognitive impairment, where that history - their memories, or crucial facts about themselves - may be hard for them to access without help.

These are by no means comprehensive - just a starting point for discussion. There is much more potential we would be happy to discuss. **We are excited about the future**.

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