Findings from DYNAMIC Work package 3: Current practice and resources for improvement

The aim of this part of the study was to co-produce recommendations and resources to improve social care for people with young onset dementia (starting under 65 years) and their families. The work package had several steps.

Step 1: The first step used convergence analysis to look across the accounts from people living with young onset dementia and their families and the survey of social care staff that we had carried out in work packages 1 and 2. These highlighted six possible areas for improvement:

- More navigable services that provide continuity.
- Better access to person-centred and age-appropriate social care.
- Improved support to understand, plan for and manage the financial impact
- Raised awareness of YOD in social care staff and the public, including in the South Asian community.
- Peer support for those with YOD and family carers.
- Support for children and young people

Step 2: We took these six themes to a consultation workshop, to discuss and agree priorities. The workshop was attended by 15 people with lived experience and 15 people from social care-related roles. It resulted in the selection of two priorities to focus on in the remainder of the project. These were:

- To raise social care staff awareness of the distinctive needs associated with YOD
- To improve strategies to help families manage the financial impact of YOD

Step 3: We looked at what was already known in these two areas by reviewing relevant published research and speaking in -depth to 12 people practising in the field.

There was no specific research on improving knowledge and awareness of young onset dementia in social care professionals. Also research on dementia training for social care staff in the community is neglected. Research on dementia training more generally has been collated recently and suggests effective training should be informed by evidence; use varied delivery methods including at least some interaction with a skilled, experienced facilitator; be made accessible, including if it is online; have elements of support from peers or mentors; and have strong leadership to make sure gains are sustained.

Those interviewed told us there is little time and money for training and training on dementia/young onset dementia is not mandatory. As a result, training tends to be online and often superficial. They gave examples about how they could sometimes fit material on young onset dementia into mandatory training. They thought that training works best when practice-focused and timely, for example when it is related to a particular client or family. They also pointed out that commissioners can demand organisations to provide training and check it is provided.

Professionals stressed ways, other than formal training, through which they gain and pass on knowledge. They learned through talking with experienced knowledgeable colleagues. They offered new staff individual induction to the area, as well as using supervision and monitoring to help develop their knowledge. Some were able to shadow in specialist young onset dementia services; others took part in reflective discussion, such as a monthly meeting focused on young onset dementia. They were aware of the need for their provision to be culturally acceptable. Social care staff also learnt through working with people living with young onset dementia in projects and some were able to raise colleagues' awareness by including information on young onset dementia during dementia awareness week.

As there was more research on the financial impact of young onset dementia, we conducted a scoping review of this area. We found 80 articles reporting financial consequences, including reduction in income, as both the person with young onset dementia and the carer's ability to work may be affected; increased outgoings, due to costs of changes in way of life and payments for social care services; and impact on children or young people, if there were fewer funds to give them support. Most of this research only touched on the issue rather than addressing it in depth. We also found twenty sources of online information on financial impact of YOD. These offered guidance on maintaining and leaving employment and legal rights in this respect. They gave tips on reducing costs and advice on advance planning around finances. They encouraged people to seek help and advised where to find specialist advice.

Many of the professionals we interviewed had roles that included giving advice on reasonable adjustments at work and facilitating conversations with Occupational Health for those still in employment. They spoke of an important part of their role being to signpost people living with YOD or caring or someone with YOD to specialist teams. They had ideas for what could improve financial management, including intervening early and having links with big employers to raise their awareness. They suggested transferring learning from allied areas such as learning disability services and establishing networks of people with an interest or expertise in the area.

Step 4: Finally we co-produced recommendations and resources, informed by the evidence and good practice, to address the priority issues. Co-production was undertaken by small groups including both professionals and people with lived experience. They directed work to produce two resources. Each consists of a short animation and accompanying written information. The one on raising awareness of YOD is targeted towards social workers and aims to be inclusive of South Asian communities. The one on finances is targeted primarily towards commissioners. They can be seen at Https://www.youngdementianetwork.org/dynamic/ where there is also an infographic summarising the key themes and messages in the two priority areas.