

# The Feeley Report: Independent Review of Adult Social Care in Scotland

## Overview

In September 2020 the First Minister announced an Independent Review of Adult Social Care in Scotland, to be chaired by Derek Feeley. We welcomed this and took the opportunity to share the experiences and views of unpaid carers and people living with dementia who had engaged in About Dementia sub-groups. The Feeley Report was published on February 3<sup>rd</sup> 2021 and is 190 pages long. This briefing summarises:

- What we highlighted as important for the review to think about;
- Some of the key things raised in the review report;
- What we think the review recommendations might mean for people living with dementia and unpaid carers.

This briefing looks at the review across a number of key themes. These are:

- Access to social care for people living with dementia and unpaid carers
  - The creation of a National Care Service on a par with the NHS
  - Self-Directed Support
  - The paid social care workforce
  - Support for unpaid carers
- Housing and independent living
  - Care Homes
  - Support for communities and voluntary organisations

The recommendations of this review have been accepted in full by the Scottish Government, but it is not yet clear how they will be implemented. This briefing is our initial reaction, and we will be talking to people living with dementia, unpaid carers, and About Dementia partners over the coming months to hear their views. As always we would like to know what you think. You can email any views to [adam.huntley@agescotland.org.uk](mailto:adam.huntley@agescotland.org.uk)

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## Background to our response to the review

About Dementia is a five-year project, funded in 2019 by Life Changes Trust and hosted by Age Scotland. We bring together people affected by dementia with professionals in the public and third sectors to influence change around policy and practice in Scotland. We do this through the mechanism of thematic sub-groups. In our first year our sub-groups focused on Housing, Transport & Mobility, Human Rights of Unpaid Carers and Prevention & Living Well. We added Technology, Sport & Physical Activity, Human Rights of People with Dementia, and Befriending & Peer Support to these in our second year. Our response to the review presented evidence collected through participative conversations with over 200 people affected by dementia and professionals over the first 18 months of our project. We also drew on policy and research work undertaken by the project during that same period. We also talked to people living with dementia and unpaid carers about the review to find out what was important to them.

## Access to social care for people living with dementia and unpaid carers

What we asked for:

- We drew attention to the challenges people face in getting access to social care when it is needed most, a process often fraught with delays at each stage.
- We highlighted that many unpaid carers and people living with dementia do not receive adequate support until they reach crisis point, which for too many results in preventable admissions to hospital or care homes.

What the review said:

- Social care should be seen as an investment in society and the economy. Crisis point should not be the entry point to the system of social care support, instead prevention and early investment should be valued.

What we think of this:

- Getting people support as early as possible is a large focus of the review and we welcome this. Delays in assessments and disruptions to care packages through moving localities have in part been addressed by the proposal for a National Care Service (NCS), which we discuss below.

## A National Care Service

### What we asked for:

- We welcomed the aim of elevating social care to be on an equal level with health care and offered that a National Care Service may go some way to addressing the postcode lotteries of provision that are experienced by some people living with dementia and unpaid carers.
- We pointed to the inequalities in charging policies and eligibility for social care. Whilst personal care is free of charge across the board, some local areas have failed to implement this and conversations with our sub-groups had highlighted the need for revaluation of charging policies across Scotland. We asked for the adoption of a model that is free at the point of delivery and considers person-centred care packages that deliver more than personal care for people living with dementia.
- We argued that some elements of social care are best served by a local model of support and pointed to the voluntary and third sector as good examples where this is happening already.

### What the review said:

- Perhaps the biggest recommendation is for the creation of a National Care Service, which would be 'on an equal footing' the NHS.
- The National Care Service would provide social care that is free at the point of need. This applies to care at home and day care services.
- The review does not include a recommendation for care home accommodation to be free to residents. Instead, care home accommodation should remain means tested. Personal and nursing care is already free to over 65's in Scotland, but the funding to provide this should be increased.
- A National Improvement Programme for social care should be introduced by the National Care Service and would focus on improving the experience of self-directed support, working towards increasing consistency in quality and safety of care homes, and enhancing the standard of social care and experience of the workforce.
- Integration Joint Boards (IJBs) will be reformed under a National Care Service and will be responsible for social care improvement, inspection, workforce, contracts and set national requirements and budget distribution. The membership of IJB's will reflect all partners and citizens including workforce representation, people who use services and unpaid carers. Appropriate support will need to be provided to enable participants to fulfil their responsibilities.

### What we think about this:

- A National Care Service that is free to all may reduce some of the regional inequalities that operate at present. However, we believe that this must be

combined with enough funding to enable the culture changes needed. We are also worried that there is not enough focus on provision by local and community based services including from charities and voluntary groups (we cover this in more detail below).

- During our conversations with carers and people living with dementia about the review it was clear that some unpaid carers struggle with the idea of requesting help, viewing this as a sign of not coping or feeling that they are burdening an already stretched system. Unpaid carers have spoken to About Dementia of being told that their needs are unaffordable. The impact this has on families is recognised in the review:

*“This [funding barriers] is not merely an accounting problem. It is a significant impediment to the wellbeing of people who use health and social care support services, because it gets in the way of early intervention and preventative approaches”*  
(Feeley, 2021).

Perhaps a National Care Service, free at the point of use and positioned on a par with the NHS may reduce carer’s anxiety around asking for help, preventing escalation to crisis point.

- We welcome the proposal to involve more citizens in the running of Integration Joint Boards and recognise this may lead to more representative outcomes. We hope the reference to ‘people who use the services’ includes people living with dementia and point to our engagement work to highlight benefit of including people with lived experience. It is worth considering the type of support that people living with dementia may require to advocate for themselves. We propose that one such model of support could be for boards to appoint personal assistants charged with managing diaries, responding to requests and making travel arrangements on behalf of board members who are carers or service users.
- We welcome the focus on improvement of SDS, however, we believe that for this to become a reality for many, access to SDS and the full range of options for people living with dementia must improve. We regularly hear from our members of the barriers they face in seeking SDS. This is not just about how SDS is delivered but also the culture of services and assumptions about what people living with dementia want and are able to do. There needs to be a culture change to see care as aspirational for people living with dementia.
- The recommendation of a National Care Service and the proposed centralisation of care services is a potentially a big change, and we are still unpacking what this may mean for people living with dementia and unpaid carers. As more information is released and reactions gathered, we will have more discussion with our members on this proposal and publish further thoughts. In the mean-time we hope that everyone involved in implementing a national care service is able to focus on the people who matter most – those with lived experience of using services or unpaid caring.

## Self-directed support

### What we asked for:

- We highlighted that Self-Directed Support (SDS) can offer people living with dementia increased independence, choice and control over their care. However, this is not what is happening at the moment.
- Too often of people affected by dementia struggle to get access to social care early enough in their journey to be able to make the sort of difference they seek. Whilst SDS has the potential to promote a preventative approach, we felt the implementation gap had stopped this from becoming a reality.
- Assessments for SDS for people living with dementia do not focus enough on the individual's aspirations, but instead on traditional services such as personal care or meal prep.
- Delays in assessments can stop SDS from having a preventative effect.
- We asked for it be recognised that self-directed support could provide an opportunity for people living with dementia to remain at home for longer by receiving support from specialist community care providers.
- We underlined our requests by relating the experiences of unpaid carers "It's not about getting any care, it needs to be the right care" (About Dementia, 2020).

### What the review said:

- Self-directed support was prominently featured in the review and spoken about frankly: "Self-directed support is absolutely the right policy but there has been a failure of implementation" (Feeley 2021).
- A National Improvement Programme for social care should be introduced by the National Care Service and would address improving the experience and implementation of SDS by placing the rights, needs and preferences of people who use services at the core.
- The review promoted SDS as vehicle for choice and control. It was recommended that the Independent Living Fund should be re-opened with the aim of delivering a national service of self-directed support that priorities wellbeing and independence.
- There were several examples of people living with learning disabilities and complex health needs employing SDS to bring independence and improved quality of life. The care received through SDS was noted as being person-centered, flexible and responsive to the changing needs of the individual.

### What we think of this:

- Whilst we welcome the recommendation for the Independent Living Fund to be reopened, we do have some reservations about the centralisation of self-directed support. There is strong evidence in support of community based approaches (Life Changes Trust 2020), and the recent pandemic has further

highlighted value of local delivery (About Dementia 2020b). We are concerned that localised community and peer support may be undervalued overlooked in a centralised model.

- In our response to the review we had proposed that SDS has the potential for creative care for people living with dementia. We imagined a care package which could include employing a dog walker to allow a person living with dementia to keep their pet for company, or a befriender to support trips to libraries, museums and cinemas.
- Whilst there were powerful examples as to how SDS could be utilised to provide person-centered care for younger adults, the sentiment did not stretch to those living with dementia and we do not feel the review has fully acknowledged the opportunity for aspirational dementia care.
- From our engagement with unpaid carers and people living with dementia we've heard of the battle they have had to gain access to SDS, and this barrier is in part due to culture. If Social Care professionals cannot envisage a care package which looks at more than meeting basic needs for people living with dementia then we will not see the change our members desperately seek.

## The paid social care workforce

What we asked for:

- The people living with dementia and unpaid carers we've spoken to have shared how much they value the paid workforce. They are also concerned about the low levels of pay they receive and the conditions they work in. This includes the challenges of daily changing rotas and fleeting visits which can make it impossible to build longer term and meaningful relationships.
- We highlighted the strong link between the undervaluing of the social care workforce and issues of gender inequality, noting that social care is overwhelmingly undertaken by women.

What the review said:

- There has been a greater focus on valuing paid care staff, calling for improved working conditions and better pay, implementing recommendations from the Fair Work Convention. The review noted that specific priority should be given to pay, travel time, sick pay arrangements, training and development, maternity leave, progression pathways, flexible pathways and pension provision.
- Many social care staff responding to the review reported feeling undervalued in the work they do, and comparisons were made between entry level retail positions, which can be better paid. It was acknowledged that poor working

conditions predominantly affect women as the care workforce is highly gendered, with 83% of the workforce made up of women.

- Significant improvements are needed in training, but care must be taken not to 'medicalise' social care and social work training.

What we think about this:

- We welcome the focus given to increasing the value placed on the social care workforce. However, we are disappointed that the same thought has not been given to the conditions of unpaid carers. This could lead to the work of unpaid carers being even more under-valued than it currently is.
- We believe that unpaid carers would also benefit from some of the benefits proposed for the paid workforce, in particular around opportunities for training and development. Carers have reported to us that their requests for basic training such as Moving and Handling are refused. We would ask that improving conditions of the unpaid workforce are treated with equal importance.
- We would agree that the social care workforce training should not be medicalised, and instead we point to therapeutic training which could improve the quality of life for people living with dementia. We would ask that the Scottish Government think creatively when exploring training options, and consider Cognitive Stimulation Therapy, seated yoga or Playlist For Life training equally valid options. There is much that can also be learned from community-based approaches.

## Unpaid carers of people with dementia

What we asked for:

- We asked for the Carers Act (Scotland) 2018 to be implemented fully, as many unpaid carers have struggled to find respite to fulfil their own basic needs. Many unpaid carers have been unaware of what they are entitled to under the act and have been overlooked in social care assessments.
- Our submission to the review highlighted the lack of respite for carers and even a few hours a week of respite was unachievable for some. We asked for increased availability of respite, and for this to be built into a package of support for unpaid carers, that is assessed independently from the person they support. If required, respite should be a regular fixture and not prescriptive at the point of crisis. We suggested that SDS would be a positive mechanism to enable the delivery of person-centred respite for carers.
- We shared the experience of unpaid carers who felt they had never been given a choice in adopting their caring role. Many unpaid carers felt unprepared and we highlighted access to training as a key issue.



- We called for the creation of a package of post-diagnostic support for unpaid carers, that runs alongside that available to people diagnosed with dementia.
- Much like the paid workforce, we pointed to the gendered nature of caring with most unpaid carers being female.
- We asked for unpaid carers to be treated as equal partners in care and shared the difficulties that unpaid carers had experienced when seeking and utilising self-directed support.

What the review said:

- Carers need better and more consistent support. Carers should be given a right to respite with an amendment to the Carers Act as required.
- The new National Care Service should prioritise improved information and advice for carers, and an improved complaints process.
- Local assessments of carer's needs should better involve the person themselves in planning support.
- Carers must be represented as full partners on the Integration Joint Boards and on the Board of the National Care Service. Both bodies will be given a new role to improve how decisions about services are made and unpaid carers should be an integral part of this.

What we think about this:

- We fully support the amendment to the Carers Act, which will enshrine respite for carers into law. However, as we illustrated many elements of the existing Carers Act are still being ignored. We believe that for real change to happen existing organisational cultures should be addressed.
- To prevent unpaid carers from reaching crisis point we recommend the respite is preventatively built in to a care package and not ad-hoc.
- We applaud the recognition of training and development that is needed for the paid workforce but feel unpaid carers should be entitled to the same opportunities to carry out the care they provide with assurance and safety. The unpaid carers we engage with want more than information and advice, they are eager to engage with standardised training that will improve both their life and the person they support. We have heard continuously that requests for training have been denied and would have liked the review to go further to address this.
- In a similar vein, the gendered nature of unpaid care was not recognised with equal weight as the paid workforce, despite the majority of unpaid carers also being women.
- It is important that unpaid carers will be included in any new commissioning models and their inclusion shows a recognition that unpaid carers have valuable input. Although, this inclusion must be felt throughout the social care system and unpaid carers must be considered as equal partners in care

too, with their thoughts and experiences treated with as much weight as any social worker or paid carer.

## Housing and independent living

What we asked for:

- We welcomed the review panel's inclusion of housing as part of the remit of the review. From our Housing and Home sub-group, it is clear that questions around access and provision of social care and housing and home are closely linked.
- Feeling part of a community and remaining at home for as long as possible are simple wants but are often challenging in reality for people living with dementia. Our conversations as part of the Housing and Home sub-group highlighted the frustration that is felt towards planning decisions that locate new residential and sheltered accommodation on the outskirts of towns and cities. This can make people feel isolated and cut off from their communities, as well as making it harder for friends and family to visit.
- About Dementia Members are also frustrated that many new builds estates are mostly large houses for families which can be hard to adapt as we age. Unpaid carers expressed the lack of options they feel are available when a decision is made to downsize, and the importance of adapting homes for changing needs throughout the life course was raised.
- Our discussions have also illustrated the effect of withdrawal of support for sheltered and wardened accommodation, sometimes at very short notice. Many worried that this could lead to an increase in falls and hospital admissions and ultimately a loss of independence for residents.
- We recommended that early intervention could be facilitated with better integration between housing and health and social care. We proposed that Housing officers are often be well placed to identify social care interventions before a crisis is reached. However the lack of joining up between social care and housing can make this difficult.
- We pointed to the inclusion of a housing sub-committee as part of the Glasgow City Integrated Joint Board as an example of good practice.

What the review said:

- A National Care Service would function to ensure effective local and national working with other public services including transport and housing, which will contribute to health and wellbeing. A person-centered approach should include professionals working together better across traditional boundaries of health, social care support and other services such as housing.

- The review relayed the frustration that people expressed when being asked to repeat the same information to different professionals, better ways of data sharing could remove this issue.
- Technological solutions may help people to live independently in their own communities and feel less lonely. But these solutions should not be imposed on people who don't want them or substitute other kinds of care.
- Decisions about what services get funded must be better linked to planning for other types of services, particularly housing plans.
- The review proposed a Home Share model, in which someone facing a housing challenge – for instance a younger adult or student – provides companionship and practical help with tasks like shopping and cleaning in exchange for low-cost accommodation. Arrangements like this are overseen by a management company for the protection and assurance of everyone involved, and can help people to retain independence.
- Housing adaptations should be seen as an investment rather than a cost.

What we think about this:

- We are glad to see housing recognised as integral to wellbeing. However the review's proposals in this area could have been stronger. Although it has been agreed that integrated working is key, we would have liked to have seen more detail as to how local and national collaboration will work in practice under the proposed National Care Service.
- We understand the impact that effective data sharing could have in reducing repetition of paperwork. The frustration felt from having to submit the same information to different services was expressed by the unpaid carers we engaged with, who commented that this process minimises their respite time and takes them away from supporting the person they care for. Effective digital processes may also release extra capacity for frontline workers. We would hope that this extra capacity could be used to address the length of time people living with dementia wait for care packages.
- During our recent Technology sub-group meetings we have explored how technology could maintain independence and improve connections for people living with dementia and attendees have been open to having more technology in their homes. However, a key theme throughout our discussions has been a fear that technology may replace some elements of face-to-face care or connection. Each person living with dementia we have spoken to has had their own unique tech preferences, therefore, we recommend any proposed technology is assessed with the person, and includes every day technology that anyone can access, not just specialised dementia technology.
- We are intrigued by the Home Share model being introduced to Scotland and are aware of the benefits that such models in England and elsewhere in Europe. The proposal itself is creative and shows willingness to think beyond traditional residential care. However, we do have concerns that whilst the

model may work well for isolated older people, we cannot assume the same for people living with dementia, who may require additional support. The company of younger adults cannot replace the knowledge of a trained wardened professional, and we worry that a '2 birds with 1 stone approach' will not provide the same level of specialised care that people living with dementia deserve. Alternatives exist which may be more dementia enabling such as Hogeweyk Dutch Dementia Village model, in which people living with dementia are free to roam in both indoor and outdoor spaces, throughout a village of safe social hubs in a high care and secure environment (Identity, O. (n.d.)).

## Care homes

What we asked for:

- We pointed to a lack of early intervention which contributes to a move from home to residential care settings, perhaps in cases where preventative care may have helped an individual stay at home for longer. We asked for early intervention to be made before situations have reached crisis point.

What the review said:

- The review agreed that a more preventative and early intervention approach to dementia can sustain people in their own homes for longer, improving quality of life.
- The review recommended that care home accommodation should continue to be means tested under a National Care Service.
- Currently, there are no regulations for care homes to be based on market needs. The review recommends that the Care Inspectorate adapt their remit to determine if care homes meet the need of the locality. The care home market should be shaped to respond to a longer-term vision that considers local need. An uneasiness was expressed about the extent to which privately-run care homes yield profits for shareholders.
- The review called for a reduction in external inspections, with the aim of refocusing who services should be accountable to, their service-users.

What we think about this:

- We welcome the shift to promoting independent living at home, over designated places for services such as care homes, though this must be combined with access to appropriate and specialised care. It should also be combined with access to and support for community based initiatives that promote connectedness and address social isolation.
- We welcome the proposed increase in resource to social care proposed through the review. However, the ongoing funding of social care for the

future will be a crucial test of the success of this review. This is something we plan to give further and more detailed consideration to in the coming weeks, and would welcome our member's feedback on this point.

- We share an unease about shareholder profits in privately-run care and agree that greater balance must be made between reinvesting profit to improve quality of care and conditions for staff.
- We know from our engagement the heartbreak that unpaid carers feel in having to prioritise appropriate care facilities over having their relatives nearby to visit. The effect of this has been more evident under lockdown, with the restrictions on travelling between different tiers, limiting the opportunity to visit even for a wave through a window. We hope that adopting a long-term strategic vision will incorporate local area needs into the commissioning process.

## Third sector organisations and community support

What we asked for:

- We highlighted the extent to which social care packages were underpinned by the support of third sector and voluntary organisations. We called for the review to address the under-funding and lack of value placed on the role of the third sector that fosters insecurity within an already stretched sector.
- We pointed to the agile response of the third sector during the pandemic and stressed the importance of localised approaches.

What the review said:

- The review recognised that third sector-based care providers had generally higher quality and called for a continuation of support packages which incorporate private, third sector and public care providers.
- Community based supports, including peer supports, should be considered for grant funding under new commissioning proposals.

What we think about this:

- We welcome the inclusion of community-based supports to be considered for additional funding, noting that many voluntary organisations have folded due to the financial pressures of the pandemic. However, we stress that current funding assessment procedure may need to be adapted in order for paperwork not to detract, or take time away, from the great quality care that has been recognised.
- The benefit of peer support has been a common theme throughout our sub-groups and we appreciate it's inclusion as a wider part of support. This is a theme that may be returned to in our Befriending and Peer Support Sub-Group.

## Summary

This document gives an overview of the recommendations of the Feeley Review (2021) into Adult Social Care, as well as our response to them. This can be summarised as follows:

- We welcome the review, the publication of the report and many of its recommendations. We are hopeful that this will see the start of a new approach to social care in Scotland, one which is empowering and aspirational. One that truly values carers (both paid and unpaid) and which delivers the best for the citizens of Scotland.
- We welcome the Scottish Government's adoption of all of the proposals contained within the review and look forward to working constructively to see the necessary changes made a reality.
- The creation of a National Care Service has the potential to reduce some of the inequalities in the current system, and putting it on a par with the NHS may see social care being valued more. However it is important not to lose sight of the benefits of community based approaches for people living with dementia.
- We welcome the increased focus on the social care workforce, including improved pay and conditions. However, unpaid carers should also have access to better conditions including training and development.
- Unpaid carers too often reach crisis point without the right support, and we welcome the review's acknowledgement that this is avoidable.
- Self-Directed Support can be transformative for people living with dementia. We welcome the focus on SDS in the review, but urge that people living with dementia are given full access to the aspirational potential of this policy approach.
- Housing is an important part of the health and social care landscape. It is about more than bricks and mortar, but about community and connectedness too. We welcome the focus on housing in the review, but would like to see more formal joining up of services. We hope that a National Care Service will not make this harder to achieve.
- The pandemic has highlighted the creativity and agility of our communities. We welcome this recognition in the review. We are concerned that a National Care Service that centralises social care, could undermine this. We call for commitments from all sides to ensure that this does not happen.

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