

POWER TO PEOPLE

Proposals to reboot adult care & support in N.I.

Executive Summary

DES KELLY & JOHN KENNEDY



ACKNOWLEDGEMENTS

We met a lot of people representing a wide range of different interests in the relatively short period to develop our Proposals Paper on the future of adult care and support in Northern Ireland. (A full list of individuals and organisations can be found in the supporting annex.) Given that our review follows a somewhat well-worn path it would have been entirely understandable to have faced ambivalence or cynicism. The experience was quite the reverse. We found people keen to express their views, share their knowledge and learning, and to challenge established ways of thinking and working. We note in our report a striking consensus about the shortfalls of the current system and a shared understanding of the need to do things differently.

We would like to thank all those that contributed to our work: responding to the call for evidence, through interviews and meetings, or hosting a visit in order for us to see care and support services and share in the learning.

We have had some spirited, and stimulating, discussions about adult care and support. People have been generous with their time, engaging enthusiastically and tolerating the many questions we asked. The level of engagement at the workshops used to test our thinking was particularly encouraging.

Transforming proposals into actions needs to build on this commitment to change through public engagement and we do not underestimate the scale of the task.

The team at the Department of Health ensured that our time was used efficiently and made the task more manageable. We have much appreciated the assistance of Dean Looney, Taryn McKeen and Ruth Todd (thankfully chocolate biscuits kept us all going at times!)

The hospitality we have experienced in Northern Ireland has been wonderful – so many scones! It is our sincere hope that this Proposals Paper really is the start of sustainable change for adult care and support.

A big 'thank you' to everyone concerned.

Des Kelly and John Kennedy



INTRODUCTION

The Panel

On 5 December 2016 former Health Minister, Michelle O'Neill, appointed us to the Expert Advisory Panel on Adult Care and Support. We were tasked with identifying a range of proposals for change; this report represents our conclusions.

While our work has focused on care and support, and in particular adult social care, it is important that our paper is considered alongside 'Systems not Structures: Changing Health and Social Care' and the wider Department of Health reform programme emerging from 'Health and Wellbeing 2026: Delivering Together'.

Why change is needed

Throughout our time on this piece of work we have sought to engage with service users, carers, the workforce, providers and wider stakeholders as much as possible. This was through meetings, site visits, a call for evidence and a series of workshops. More than once during this review we have been encouraged to be radical in our proposals. This is encouraging because, in our view, the system is collapsing in slow motion. Maintaining the status quo is not an option. Nor is a piecemeal approach to reform. The agenda we have set is ambitious, and we do not underestimate the challenge of delivering it, but it is a challenge which must be tackled if a total collapse of the system is to be avoided.





THE VALUE OF SOCIAL CARE

Every year in NI, Health and Social Care (HSC) Trusts spend over £900m on adult social care including services like day care, domiciliary care, residential care and nursing home care. To the many thousands of people who receive those services – and their families – they are vital supports. And with an ageing population, it is a system that many more of us will need to avail of in the future.

Yet public knowledge and understanding of adult social care is limited: what it is, how to access it, who is eligible and how is it paid for. And this means that there is a lack of knowledge of the challenges that mean that the system needs to change: growing demand and a limited menu of support which fails to recognise changing needs and expectations means there will be an ever widening gap between what is available and what is needed. This change means looking at when does support become available and what should it look like. It also means taking a wider look beyond social care itself to those other services that can provide complementary support, for example, housing and transport.

Proposal One

The Expert Advisory Panel proposes that consensus on the need for, and direction, of transformational change is achieved and that the leadership responsibilities for the adult care and support system are made more explicit.

It is proposed that a cross-government initiative, led by the Department of Health, is undertaken to raise awareness of the purpose and value of adult care and support. The Panel also proposes that the Health and Social Care Trusts, together with other key bodies in Northern Ireland, take a specific lead in promoting the positive contribution of adult care and support.



THE CITIZEN AT THE HEART

A person-centred vision for adult care and support services, in whatever form they take, wherever they are offered, and whoever delivers them, is intended as a defining feature of this Proposals Paper. Personalisation in the provision of social care must be seen as fundamentally altering the way in which engagement is undertaken. Commissioners and providers working in partnership with citizens (as users and carers) is vital to drive change and innovation - neither party can effectively bring this about on their own.

But we recognize that promoting independence to maximise choice and control is easy to write into a mission statement but can be more challenging to deliver. One of the key challenges is risk: fear of blame, and the consequences, and a lack of trust may in this way contribute to restricting choice and control for individuals. We also recognize that people may need assistance to exercise informed choices to enable them to reach their goals and outcomes in ways that do not compromise their need for safety. This may mean a need for brokerage and advocacy to make this real for some individuals.

Proposal Two

The Expert Advisory Panel proposes that models of self directed support become the norm in order to empower citizens with effective demand. Further priority should be given to how Self Directed Support funds could be used as catalysts to create and shape a diverse market of care and support provision, and we propose that mechanisms to stimulate such models are facilitated as a matter of priority.



FAMILY CARERS – VITAL PARTNERS FOR SOCIAL CARE

During the course of our evidence gathering the Expert Advisory Panel heard from carers groups and individuals and it is impossible not to be humbled by the scale and generosity of their love and commitment. There can be little doubt that family, or informal, carers already contribute the largest share to supporting people and that enabling carers to continue to offer support is essential to the future sustainability of the adult social care system.

Yet we have heard how hard and lonely the caring role can be. Although every caring situation is different, because families and neighbourhoods are different, we heard similar concerns from carers in many varying situations. They often feel out of sight, undervalued and neglected.

In our view we need to find a way of supporting, understanding and valuing the carers' role more explicitly and honestly. Access to the right information at the right time is a key wish, as is the availability of appropriate short term breaks so that carers can have regular respite from the role. The main request, though, is to be acknowledged and recognised and truly valued.

Proposal Three

The Expert Advisory Panel proposes that the rights of family carers are put on a legal footing and that a strategy to bring them into the heart of transformation of adult care and support is adopted.



BUILDING RESILIENT COMMUNITIES

Age, frailty or disability does not, of itself, result in needs which require professional care services. But we may have social needs - having company, having something worthwhile to do, staying in touch with friends and interests – and, as individuals, each of us will have particular choices and expectations, hopes and aspirations.

Notions of community cohesion, engagement and empowerment have long featured as a strand of social work and social policy. There are a number of community based networks of support already out there, but they tend to be very local and are rarely scaled up so that other communities can benefit too.

It is our view that the community approach, which gives people a 'navigator', can help to ensure that people are guided and assisted to get what they need from the care and support system. And Community Planning offers huge potential to strengthen collaboration between the wide range of organisations operating in their areas and their communities to shape and deliver improved services and outcomes for the benefit of local people. Working in this way we can help shift the emphasis of the system from crisis response to prevention and early intervention.

Proposal Four

The Expert Advisory Panel proposes that neighbourhood based, preventative and citizen-focused community support models are encouraged and enabled. This should include the concept of a social worker-led Community Navigator role with such models available to every locality in Northern Ireland.

Proposal Five

The Expert Advisory Panel proposes that the reform of adult care and support is fully aligned with the Community Planning responsibility of local councils. This should include consideration to the development of a more diverse range of funding vehicles such as Social Impact Bonds to create incentives and capacity in the development of resilient communities.



THE PROFESSIONAL WORKFORCE IN SOCIAL CARE

Care work is highly skilled. To be good at it you need a high degree of emotional intelligence, negotiating skills, and kindness in spades.

Yet we surround care workers in a mire of paperwork and suspicion. Care workers receive amongst the lowest wages in the labour market: in short, a low paid, high turnover and undervalued workforce is a poor way to ensure the quality of care we demand.

We need a new model, one which recognises and builds on the skills and experience of staff by empowering them to make decisions and create a more human and relationship-centred ethos into social care. Crucially, within that new model, the care sector should be raised above the bottom of the pay market to enhance its ability to attract the best people. We also need to proactively improve the status of care work within society. The national registration of care workers in Northern Ireland gives an opportunity to do that, acting as a vital connector of the workforce, improving the professional regard for care workers and communications and information around training and development.

Proposal Six

The Expert Advisory Panel proposes that the care and support sector should be, at least, a Living Wage sector as a first step to recognising it as a professional workforce. In the longer term the vision should be to equalise pay and conditions across the social care workforce.

Proposal Seven

The Expert Advisory Panel proposes that the Northern Ireland Social Care Council (NISCC) leads efforts to elevate the status of the social care workforce, through registration and the development of a shared induction, training and career development standards. That the NISCC further considers the representation of the social care workforce in the development of a professional body to ensure that the voice of frontline staff is effectively heard in the transformation of care strategy.



THE 'MARKET' FOR CARE

What is the social care market for and what is it intended to deliver? Is it really a 'market' in the conventional sense? Is it consumer-led? In effect, many care providers see themselves as having only one customer – the HSC. And the market as it stands only appears to have one actual competitive dynamic: the squeeze on cost.

It is our view that the system of adult care and support needs to be more focused on developing, encouraging and spreading a far greater variety of interventions, supports and services than can currently be accessed flexibly and individually at a community level. The culture around care and support services needs to be one of everyone's 'skin in the game', appreciative enquiry and mutual support. Commissioners and providers need to be honest about costs and transparent about priorities. This will have a cost and, reflecting that expense, we are of the view that where people can afford to contribute to the cost of their support, wherever that support is provided, then they should be asked to do so.

We have also heard concerns about the quality of some existing services. In our view, achieving quality consistently in professional social care cannot ever be achieved through regulation in isolation. Many other factors are important. The engineering underpinning the sector, including recognition of the true cost of care, needs to be sufficiently robust too. Alongside this, it appears crucial to us that there is an effective approach to market shaping informed by a capacity strategy that uses data on projected demand to inform and implement the planning of the supply of professional social care services.

Proposal Eight

The Expert Advisory Panel proposes that commissioners and care providers work collaboratively and openly together to develop and introduce a framework based on an agreed true cost of care which includes agreement of a 'sustainable return' for providers. This should recognise the workforce considerations set out in Proposals 6 and 7.

Proposal Nine

The Expert Advisory Panel proposes that the Department of Health should ensure that charging arrangements should be based on the principle that where a person can afford to contribute to the cost of a service they should do so. This principle should be applied consistently and equitably across all adult social care models.

Proposal Ten

The Expert Advisory Panel proposes that the HSC Trusts make explicit their commitment to a process for planning the supply of care and support services and which involve all stakeholders early in developing the strategic vision for future provision.

Proposal Eleven

The Expert Advisory Panel proposes that the Department of Health considers whether additional powers should be given to the Regulation and Quality Improvement Authority to regulate the professional care market. In particular assuring adherence by care providers to the principles in Proposal 8 including the oversight of a fair and agreed return.

Proposal Twelve

The Expert Advisory Panel proposes that HSC Trusts are enabled to more effectively discharge market shaping responsibilities. In this way requirements to facilitate self directed support and encourage community based models of intervention alongside formal systems of care and support can be monitored.



SYSTEM ALIGNMENT – MAKING INTEGRATION MEANINGFUL

Despite the integrated structure of health and social care in NI, integration does not appear to be working for people in need. Somehow we need to align everyone to work together in the same endeavour. Only when all parts of the system are working seamlessly together, with parity of esteem, will the full potential of the adult care and support sector be realised. We believe the situation could be significantly improved by considering some key relationships, e.g. between primary and community care; between hospitals; care homes and domiciliary care; and between social care and housing. Care homes, if properly integrated and supported, could provide an alternative to hospital admission and most definitely be a place for early discharge and rehabilitation. Better housing would enable people to live independently and thus remain in their own communities, with or without formal care or family support.

There is also the potential for improved outcomes for individuals and savings to the system if expertise and need could be brought together in a well matched and timely fashion. We believe this could be better achieved by having flatter 'one point of contact' Multi Disciplinary Teams aligned to neighbourhoods and strongly connected to GP's and Community Navigators.

Proposal Thirteen

The Expert Advisory Panel proposes that the Department of Health oversees the introduction of a whole-systems approach to facilitating joint working between commissioners, health services and care providers which include a clear mechanism for involving people receiving services and carers within all the HSC Trusts.

Proposal Fourteen

The Expert Advisory Panel proposes that the HSC Trusts promote a collaborative, rather than competitive, ethos which fully involves all key stakeholders in the care and support system.

Proposal Fifteen

The Expert Advisory Panel proposes that the Department of Health and the HSC works more closely with the Department for Communities and NI Housing Executive around future strategies for specialist and supported housing to ensure more effective alignment between housing and social care.





TOWARDS A NEW CONCORDAT

It is the view of the Expert Advisory Panel that a 'shared vision' for the future of care and support services is required as part of a fundamentally new approach. And a vision that is shared by everyone – not just those that know because they are in contact with services or work in the sector.

Our vision is to place the person receiving care and support at the centre, building on their strengths and, as far as possible, complementing family and community resources. We describe this new settlement as a Concordat. A co-produced agreement in which citizens are able to be well informed about their entitlements and rights as well as their responsibilities and duties. The Concordat would be an opportunity to make explicit policy intentions of personalisation, prevention and enablement, support for carers, developing community capacity and intermediate care for example. Through public education the boundaries between social care and other public services can also be clarified.

Proposal Sixteen

The Expert Advisory Panel proposes that a Concordat is developed as the major means of stimulating a comprehensive debate, and agreement, with the public about the principles underpinning a transformed adult care and support system, including its purpose, how it is organised and funded. The debate should also review attitudes to risk and how citizens can be more enabled to be the determinants of their own risk tolerance and mitigations.

“ Only through a co-ordinated approach of taking forward the proposals will a successful implementation be possible and real change achieved. ”

EXPERT ADVISORY PANEL

