

POWER TO PEOPLE

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

Expert Advisory Panel on
Adult Care and Support

DES KELLY & JOHN KENNEDY



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ACKNOWLEDGMENTS

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

“ Be radical!
”

STAKEHOLDER COMMENT



INTRODUCTION

The scope and context of the review

This review is part of the wider Reform of Adult Care and Support project in Northern Ireland which involves three stages:

- The initial **consultation on 'Who Cares? The Future of Adult Care and Support in NI'** to build the consensus for change (September 2012 – March 2013);
- The development of a **Proposals Paper** (this report) which was undertaken between December 2016 and May 2017, and subsequent policy consultation document which is expected to be produced in 2018; and
- A **Final Strategy** setting out future direction and funding reforms that will be required.

As set out in the terms of reference (see the supporting annex) this review covers care and support for all adults: older people, people with physical, sensory or learning disabilities, and those experiencing mental distress. The care and support services they receive are primarily the responsibility of the Department of Health. However, services provided by other government departments that can support people including housing, transport, health and education are also touched on in the report. This is a considerable task particularly in the timescale!

Of course, the Expert Advisory Panel recognises that there are significant differences between the needs of people who receive adult care and support services and the specialist provision designed to support them. For example, a young person with a learning disability experiencing the transition to adult services, a person with mental ill-health moving from a long-stay hospital setting to supported living or someone living with dementia in a care home will have very different needs and receive different services under the care and support umbrella. But we also firmly believe that our need for care and support should not define us. We are all different as individuals more



than we are different because of our age, abilities or care and health needs. We are ourselves because of who we are and we will argue in this paper that who we are as people should be the starting point for a transformed adult care and support system. One that recognises, and celebrates, our ambitions and contribution. One that values who we are regardless of our age, gender, ability, sexuality or ethnicity; one that focusses on us as people and one based on our individual unique value and human rights.

In reviewing adult care and support in Northern Ireland we have witnessed considerable consensus on what is wrong with the current system and a strong shared understanding of the problems. A substantial proportion of the evidence received reinforced this premise. However, in this Proposals Paper we want to focus positively on the future rather than restate the shortfalls of the past.

It is important that our paper is considered within the wider Department of Health reform programme emerging from 'Health and Wellbeing 2026: Delivering Together'. While the time constraints have restricted detailed analysis, the Expert Advisory Panel have sought to set out clearly the principles which we believe should both underpin, and guide, the transformation process to reform adult care and support services in Northern Ireland. It is our view that, as the full force of continued public spending constraints combine with changing demographics and rising demand and expectations, the context for adult care and support will be forced to change. It is happening already

- a system collapsing in slow-motion.



An unassailable case for reform

More than once during this review we have been encouraged to be radical in our proposals. The challenges are great and arguably the solutions have been resisted for some decades. **We believe that there is now no choice but to be radical.** A mixture of incremental adjustments is no longer sufficient to keep an unsustainable system working.

It is the view of the Expert Advisory Panel that fundamental reform of adult care and support is required to avoid a total collapse of the system with all the implications this would have for those in need. This requires both leadership and ownership across the whole system of care and support.

Furthermore, we argue within this report that a 'pick and mix' approach to the proposals is not appropriate. Systematic reform of the whole system of adult care and support is necessary to achieve the ambitious commitment in Delivering Together to tackling the pressing issues facing the social care and health system in Northern Ireland. Of course, Northern Ireland is not alone in

these challenges. The same pressures and the pressing need for reform are true for most developed countries. In the course of this review we have formed the view that there is an appetite for changing the way in which adult care and support is organised and delivered in Northern Ireland, with an evident commitment to make the changes that are needed. In our concluding section we turn to the idea of a Concordat as the means of stimulating a discussion with the public about the future of care and support and how it should be funded.

The scale and scope of this review, and the time available to complete it, have meant that our proposals cannot be fine grained and detailed. Although some detail was specified in response to the Call for Evidence we are mindful that substantial further work will be necessary, particularly for the proposals to be developed into actions. In addition, it is our view that it is not appropriate that the proposals are seen to be overly prescriptive. The policy consultation from the Department of Health that will follow this review paper, together with the public response, engagement and discussions, obviously need to be a part of shaping the proposals into steps for action that fundamentally change the way that services are operated and delivered. We have endeavoured to distill the key things we have learned about what people say is wrong with the current system to create a set of proposals that can be used to give greater clarity and priority to transforming adult care and support. If it was easy, obvious or painless to deliver the change that is necessary to the adult care and support system, arguably it would have been done already. **The leadership challenge of making care services fit for the 21st century is significant.**

Our proposals are an attempt to synthesise the excellent examples of innovation and creativity we have seen in order to address the shortfalls that have been raised with us. We believe that the proposals, in themselves, could be the very drivers of transformational change. It is our abiding hope that the proposals included in this paper can form the basis of discussions with the widest interests as a 'social movement for change' in the way adult care and support in Northern Ireland is organised, delivered and funded. Furthermore, that perceptions of its purpose and value are similarly transformed.

During the period of this review we have met with in excess of 100 people: they include people receiving care and support, their carers and families, social care staff, voluntary organisations, independent care providers, commissioners, regulators, policy makers, trade union representatives, and a range of care and health professionals. We are hugely grateful for the generosity with which we were received.

The Call for Evidence

A Call for Evidence was launched on 5 December 2016 at the beginning of our work, and ran for six weeks until 23 January 2017. This was intended to provide an opportunity for stakeholders to share examples and evidence as to how care and support can be improved to meet growing demand and changing expectations, and to provide suggestions as to how the care and support system can be sustainably funded to meet those needs.

We received 46 separate submissions to the Call for Evidence, from a range of organisations and some individuals, and as many papers again in supplementary evidence. Some of the people we met continued to submit comments and information throughout the time we

were working on the review. The quality of evidence received was very high, and it provided a sound basis for us to begin our work.

During the Call for Evidence we also met with a range of stakeholders and visited some innovative services around Northern Ireland. We were impressed by everyone we met, by their willingness to engage, their hospitality, and their readiness for change. The conversations we had, the people we met and the services we visited, have all played a part in shaping our thinking during the completion of the review.

Engaging with stakeholders

Throughout the period of the review, the Expert Advisory Panel has worked with service users and carers through the Adult Care and Support Reference Group, facilitated by the Patient Client Council. We met with the group in February 2017, when we presented our early findings following the Call for Evidence. We met with them again in April 2017 as we worked to finalise this Proposals Paper, and the views shared and suggestions made were valuable and have greatly helped to shape our final report.

We also held three stakeholder workshops (in Craigavon, Derry and Belfast) in early March 2017 which were designed to test our thinking around the key themes of:

- choice, control and community engagement;
- building capacity and sustainability;
- the workforce for adult social care.

Over 130 people attended the workshops, with some choosing to participate in more than one and others writing in with further comments after the events. There was a high level of engagement across the many interests represented at the workshops. There appeared to be a recognition that the current structure of social care, in terms of commissioning on the one side and providing on the other, was significantly out of step with the demands and expectations now being made of it. Crucially too, the definition of adult social care is considered to be drawn far too narrowly.

Further detail on the response to the Call for Evidence, including meetings with stakeholders and visits to services, is provided in the supporting annex provided alongside this report.

The structure of the Proposals Paper

The scope of this review covers all adult care and support. We have sought to write the report with this in mind whilst acknowledging that there are inevitable important differences between people with different needs, personal histories and family circumstances. Being true to the principle of individual support which has the person, as citizen, at the centre is more important than 'client' classifications that group people's needs according to their age or to a specific condition.

The following sections consider the areas in need of reform. Each section analyses a key theme pertinent to the effective delivery of adult care and support, although we avoid detailed policy tinkering to concentrate more on trying to describe and articulate the essential principles for our proposals. We believe that the principles are relevant to all adult groups receiving care and support, although we are mindful that specific policy will need to be agreed to ensure that individuals receive services that are appropriate to their specific needs for which more detail will be necessary. We do not underestimate the leadership that will be required to take forward our proposals and develop a framework for implementation.

Section 2 – The value of social care

The nature and importance of adult care and support and the contribution it makes to personal wellbeing, health services, society and the economy is outlined in this section. The key themes that have been raised with us as evidence to the review are introduced. Why we believe social care needs to be elevated to a far higher status in both government priorities as well as in the minds of citizens, families and communities is discussed.

Section 3 – The citizen at the heart

Here we set out our thinking in relation to a human rights approach to care and support. Putting people, rather than structures and systems, at the centre of our interests. We explore ways in which self directed support could become the organising norm for adult care and support services.

Section 4 – Family carers – vital partners for social care

This section acknowledges the significant contribution made by family, friends and other informal carers to the health, well-being and human rights of adults with support needs. Currently, they may be seen as the bedrock of care, as their contribution is the principal way that most people experience care. It is vital that they are treated as partners.

Section 5 – Building resilient communities

People live in homes and communities, not in social care systems. Here we consider how an asset-based community approach could be fundamental in underpinning the structure of a transformed approach to care and support with a crucial role for social workers.

Section 6 – The Professional Workforce in social care

Whilst we believe that adult social care is, and should be, much more than 'paid' and formalised services, these will always be required. The people who care for us may be doing it for a living but they are people too. In this section we outline how the workforce should be supported and valued.



Section 7 – The 'market' for care and support

Much has been said and reported to us in relation to the inadequacies and dysfunction of the social care 'market'. It doesn't function in the way we need it to do. In this section we set out what might be done so that an effective and responsive market can be sustained and thrive.

Section 8 – System alignment - making integration meaningful

The fragmented arrangements that are a common feature of adult social care services as it relates to health, housing and other disciplines have long been seen as problematic. Policy exhortations to bring about a joined-up response and partnership working have pointed to the benefits of achieving more integrated working. In this section we discuss the need for the various systems relevant to adult care and support to be properly aligned.

Section 9 – Towards a new Concordat

In the final section we summarise our thoughts and set out the underpinning principles of a new Concordat. This is envisaged as a new settlement between individuals and the State with a recognition that rights are balanced by risks and responsibilities on both sides.



From reviewing to action

Whilst the review has been welcomed, the responses to the Call for Evidence encouraging and the discussions positive, concerns were raised with the Expert Advisory Panel on the seemingly slow progress of change: "plenty of reviews and lots of evidence but no action". This statement echoes the comments made in Professor Bengoa's report 'Systems, not Structures' which rather compellingly refers to "review fatigue".

We sincerely hope that this paper will not be read as 'just another report' but that it will help in encouraging the radical rethink or 'reboot' we believe is necessary to challenge the current approaches, attitudes and established ways of delivering adult care and support. In this way it can **embolden a genuine public movement for change and transformation.**

“ We need a system of care where the individual and their family are in control of the nature of the social care provided, giving them realistic choice. ”

NI SOCIAL CARE COUNCIL



THE VALUE OF SOCIAL CARE

This section sets out the nature and the importance of adult care and support and the contribution it can make to personal wellbeing, health and society in general. It introduces the key themes that have been raised with us as evidence to this review and explored in discussions with many different people with an interest in the care and support system in Northern Ireland.

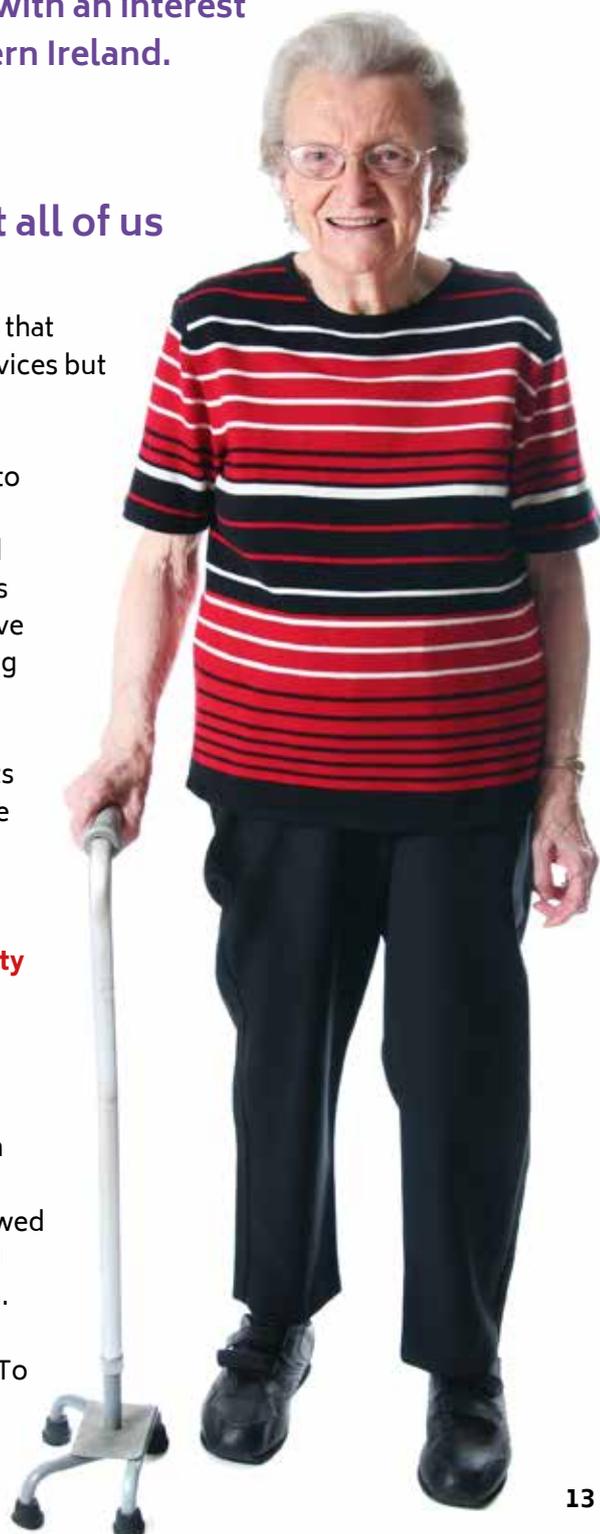
Social care is personal ... and about all of us

A good system of social care can transform lives - it's that simple. Not just for those who receive social care services but their families, friends and communities too.

And yet it is something of a puzzle that our attempts to create the kind of system we want – services that are responsive to individual need – have become tangled with the 'task' of delivering social care. The processes of assessing, organising and managing appears to have become ever more complex. The process of providing personal care and support has, in turn, become an activity so often characterised by risk assessments, policies and procedures, rules and regulations. Efforts to safeguard and protect the rights and independence of individuals in need of support has led to an 'industry' of inputs and processes which threaten to overshadow, or subvert, the very outcomes they seek to enable. **The notions of wellbeing and quality of life can so easily get lost in the structures and architecture of a managerial system.**

In undertaking this review the Expert Advisory Panel have been struck by the many different ways in which discussions, with a wide range of different people in Northern Ireland, have emphasised a need for a renewed focus on the individual citizen at the heart of care and support services. We warmly welcome this approach.

Social care is personal. It starts with the individual. To be truly personalised it means genuinely listening



to the people who receive care and support, their families and friends, to help them reach their goals and aspirations. It is vital therefore that they are actively involved at all levels of decision-making about how their needs are to be met. But care and support is also personal in the sense that we have a shared interest in knowing that there is a system of care and support should we, or any member of our family, ever be in need of such services.

Being clear about what is meant by adult social care

There are very many definitions for social care. The definition we have favoured for this Proposals Paper, because it is so firmly rooted in the values of human rights, is taken from the Social Care Institute for Excellence (SCIE) and was developed to define excellence for a report originally commissioned by the Care Quality Commission:

"Excellence in social care is rooted in a whole-hearted commitment to human rights, and a continuous practical application of that commitment in the way that people who use services are supported. People who use services are demonstrably placed at the heart of everything that an excellent service does."

(A definition of excellence for regulated adult social care services in England p4)

The definition adds:

"We have identified four essential elements of excellence. Three of these are about improvements in people's lives as a result of using the service. These outcomes are:

- Having choice and control over day-to-day and significant life decisions;
- Maintaining good relationships with family, partners, friends, staff and others;
- Spending time purposefully and enjoyably doing things that bring them pleasure and meaning.

The fourth element relates to the organisational and service factors which enable these outcomes to be achieved and sustained... The four elements interact with each other. They do not stand alone. Without choice and control, a person cannot spend their time in ways they would wish... An excellent service, therefore, will be one that recognises the interplay between these four elements, and which addresses them simultaneously." (2010, p5)

This fourth element is the service and its operational management that sets the standard and makes possible the outcomes defined by those using services. Throughout this report we typically refer to 'adult care and support' as a descriptor for the social care services for all groups of adults covered by our terms of reference.

Policy tensions within social care

Professor Jon Glasby from the University of Birmingham identifies a number of policy tensions¹ within adult social care in the third edition of his seminal introductory text:

- whether to involve people with experience of using services because they are 'customers' or as 'citizens' with a right to greater choice and control;
- whether to support informal carers, exploited by formal services, to acknowledge their needs and rights, or to focus on the needs of carers as a means of helping users and thus reduce demand on services;
- whether to support people with long-term conditions because they are citizens with the right to live independently, or as a means of reducing reliance on expensive hospital services;
- how best to promote more joined-up responses to need in a system that continues to assume that it is possible to distinguish between people who are sick and those that are frail and disabled.

These tensions were clearly evident during the discussions which have informed this review. As a consequence, we have sought to address the issues head on. Professor Glasby argues that in the past it was possible to do a little of each of the 'either-ors' listed above as a short term fix. To an extent, in England particularly, this has worked to prevent a complete collapse of the care system to date, although cracks and gaps have come to characterise a sector openly seen as in crisis.^{2,3} According to Professor Glasby "the jury must remain out on the extent to which the current system can continue to contain these contradictions and tensions".

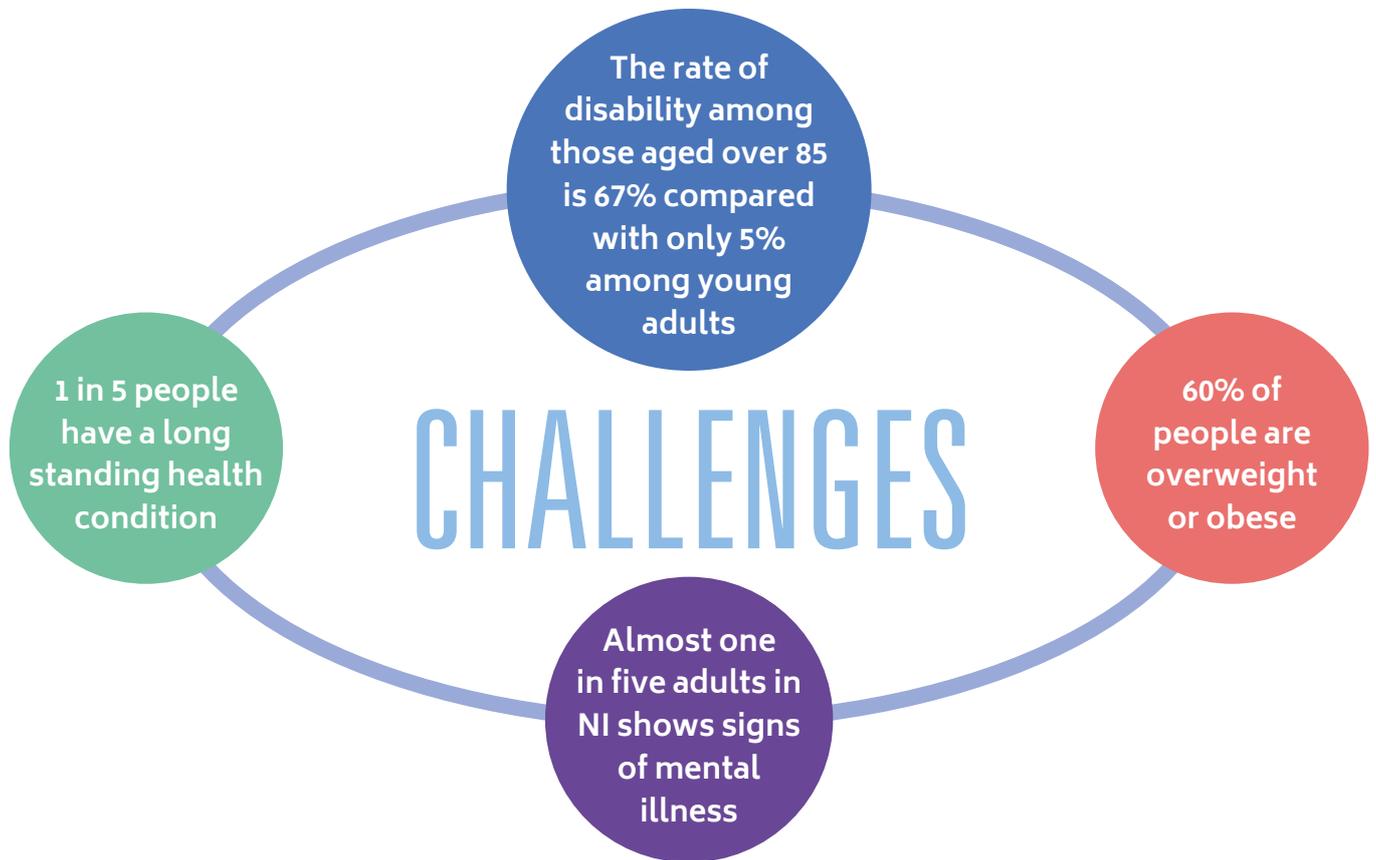
We have concluded that it is no longer sustainable to merely tinker at the edges of a broken system

It was suggested in one meeting with stakeholders that change might be forced on the care sector in Northern Ireland by the system "imploding". Arguably policy tensions have now reached a level where something will have to give. To repeat a phrase which has arisen many times during our discussions: "we need action, not another review and another report!"

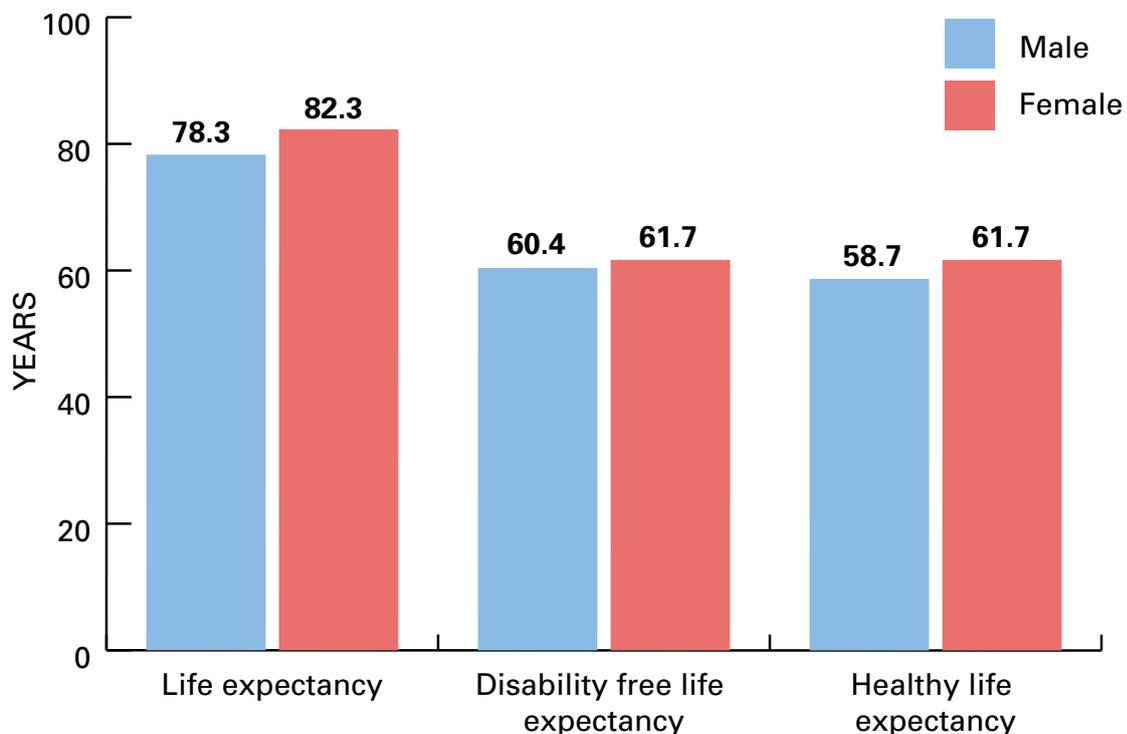
Demographics and changing life expectancy – again it's about us

Many reports precede this review including the recent report by the Expert Panel chaired by Professor Rafael Bengoa, 'Systems, Not Structures: Changing Health and Social Care (2016)', which set out some of the challenges already present in the current population:

1. Postscript to 'Understanding Health and Social Care', 2017, p181
2. Nuffield Trust 2016 'Social Care for Older People: Home Truths' Kings Fund
3. NAS, Mencap, Leonard Cheshire, Sense, Scope 2013 'The other care crisis: Making social care funding work for disabled adults in England'

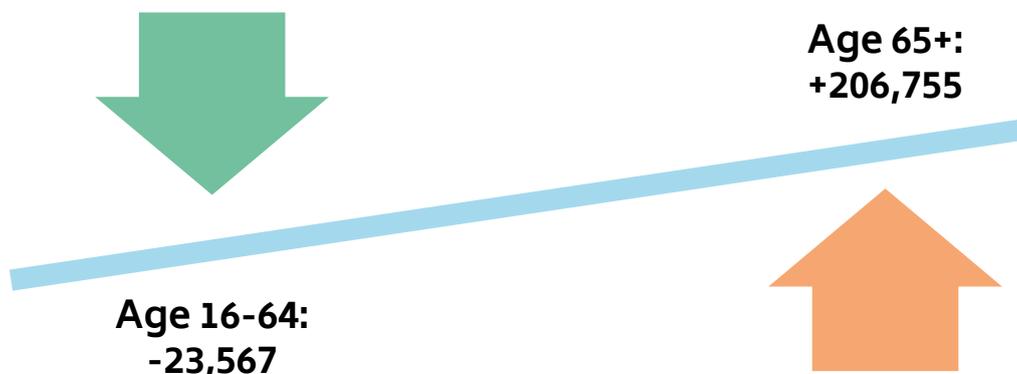


This means that many of us will face illness or disability in our lifetimes. As outlined in the diagram below, both men and women can expect to live approximately 1/4 of their lives in ill-health or with a disability.⁴



4. 2016 (DoH) Health Inequalities Regional Report

The implications of this are all the starker when we consider how demographic change will impact on society: by 2039 our younger population will have decreased while our older population will have grown enormously.



NISRA (May 2016), Sub National 2014-Based Population Projections

It is important therefore to be alert to the fact this is not about 'them'. The likelihood that we will all be touched by the demand for social care for ourselves, within our families and communities is overwhelmingly clear - **it's about all of us!**

Social care is broad

The broad reach of adult social care means that it shares borders with many other disciplines that are important to personal wellbeing and quality of life. Yet too often adult social care is simply far too narrowly defined. Social care has an important relationship with health care services; this can be seen from the demands on GPs and Emergency Departments, which comes sharply into focus when people are unable to be discharged from hospital care. There are also similar overlaps with housing, education, work, leisure, transport and criminal justice services. There is a crucial element of interdependence, to these overlaps and relationships. Furthermore, social care is dynamic because circumstances change: people can improve, recover, or regain independence, just as they can experience an increased need for support. For these reasons it is vital that adult social care is acknowledged to be multifaceted, subject to and benefitting from multidisciplinary partnerships and relationships. Social care should not be seen as simply linear or one-way. Ideally social care is outcome-based - not simply about the 'processes' or the 'inputs'. An outcome-based focus to meeting needs acknowledges that wellbeing and quality of life as defined by people receiving care and support, and their carers, are paramount. Notwithstanding the fact that such aspirations are more easily said than done.

It is our view that the provision of social care has a crucial bearing on the sort of society we really want to be. **Social care should be recognised as a vital and positive part of the infrastructure of society and the economy.**

During the review discussions we have been urged to be radical in the approach to formulating proposals. Our sense is that this is a reaction to the overwhelming view that the current system of adult care and support is considered unfit for purpose and unsustainable in the longer term. A strong theme emerged from the Call for Evidence, and the discussions

we have had, that the inadequacies of the present system have either been ignored or periodically tinkered with but to little lasting effect. However, we see little benefit in re-analysing what may be seen as past failures of the care and support system. We are equally mindful that producing another report on adult social care will be of limited value unless it can be a genuine catalyst for transformational change. **It is our hope that the proposals will be used to stimulate a serious public debate about the future of adult care and support in Northern Ireland.**

If we have been in any way ambiguous we will have failed in this task. If our proposals are considered too subtle, we will have missed an important, timely opportunity to offer the radical options we believe are necessary to build a sustainable social care system for the future.

This Proposals Paper seeks to keep the individual as the central focus of attention. It starts therefore with the person and subsequent sections build on this fundamental principle in ways that refocus attention on their assets rather than their needs, rights rather than risks, and outcomes rather than processes.

Re-valuing social care

The question of the value placed on adult care and support by the public and, as a consequence, the status ascribed to the tasks and activities of social care has arisen many times during the course of this review. Public perceptions of social care differ significantly from that of health care. In part this may be because fewer people have direct experience of adult care and support services. As the impact of changing demographic trends is felt we might expect that this will change. More people might actually experience care and support services or at least become aware of the need for such services.

Being clear about the purpose of adult care and support as strongly rooted in improving wellbeing and quality of life for individuals is vital to challenging the views that people may have of care and support services. So too improving understanding of the need for a more individualised approach to meeting care and support needs. Quality of life is linked to personal relationships and networks of support as well as opportunities for development to enable people to fulfil their potential. The way in which care and support services are structured and delivered has an important part to play in promoting the value of person-centred, local models. Notwithstanding the need for greater responsiveness, flexibility and integration of services with more openness and transparency in the way they operate, care and support services are a lifeline for many people and their families.

It is plainly wrong to view social care only as a cost. The way in which social care services are integral to many other aspects of people's lives highlights the ways in which it contributes to society and the economy. Support services can enable people to be independent in so many different ways:

- to continue working, both in a paid capacity or as a volunteer;
- to provide informal care;
- to undertake education; and
- to help to keep people out of institutions and live in their own homes.

Harnessing the consensus for change

Throughout the discussions that have informed this review the Expert Advisory Panel have been struck by the overwhelming appetite for change. This experience mirrors the findings of the Bengoa Report 'Systems, not Structures' (2016). A strong sense has emerged of a social care system that no longer functions either effectively or efficiently. Care and support services have become reactive rather than proactive, and selectively reactive as well. This is the consequence of a variety of factors and forces.

In addition, there have been few incentives for the system to operate differently with too many obstacles to changing the status quo within social care or across the wider health and care systems. Thus, it is our conclusion that incremental adjustments at the margins are unlikely to have the necessary impact to make a meaningful difference, and that without radical transformation it will be all too easy for things to fall back into the familiar shape they have become.

“ We need to understand the wider role of social care, including its links with Councils, housing providers, voluntary sector, private sector and business. ”

WORKSHOP COMMENT

We have been greatly encouraged by the consensus of opinion that to continue with a social care system that does the same things in the same ways is as nonsensical as it is unsustainable. Given we have met such a high degree of readiness for change **it is not unreasonable to ask why change hasn't already happened**. There is certainly plenty of analysis and opinion about what has led to the current situation and why the adult social care system is not working as well as it should. And yet for all the analysis there appears to be a paucity of data for some important aspects of adult social care which gets in the way of complete understanding. We have found that up-to-date information is patchy at best. In addition, the broadness of the interests together with the fact that the power for change is spread thinly across the system might explain how the system has so far resisted change.

Rising demand and rising expectations create additional pressures. Coming on top of a period of austerity in the public sector, it is not surprising that the strains on the adult care and support system are beginning to show. But the need for change is also about the transfer of power from professionals to citizens. We know this is hard for so many reasons. It is the view of the Expert Advisory Panel that this requires considerable leadership - political, professional and personal - assisted by a willingness to both encourage and facilitate new models and new ways of working. Again, **this is easy to say but difficult to do**.

The 'systems, not structures' line used as a title for the Bengoa report graphically illustrates the challenge of ensuring that the provision of health and care is properly organised and

working effectively. It is clear that this applies equally well to describing the current shortfalls of adult care and support. There is also a recognition for that for many people more money, in itself, is not the answer.

The demographic and demand pressures facing Northern Ireland mean that resources, without reform, will merely delay the inevitable collapse of the social care system. Whole-systems change to transform and reconfigure health and social care was similarly a major theme argued by Professor Bengoa. The evidence provided to us and the discussion we have had with organisations and individuals has further highlighted this "unassailable case for reform".

Despite the apparently integrated structure of health and social care that exists in Northern Ireland, it is our view there is still insufficient joined-up working, and we consider this further in our section on systems alignment. **Unintentional barriers somehow seem to perpetuate the status quo of a silo mentality.** There is a need for far greater honesty and transparency with the public as well as between commissioners and providers. We consider this issue in more detail when we turn to the matter of shaping the market for adult care and support and the shared responsibilities of commissioning and providing services in section 7.

The leadership imperative

There is a political priority for the value of adult social care and its contribution to society to be clearly articulated and properly acknowledged. Building on the apparent consensus for change by setting out the vision, purpose and potential of adult care and support would be greatly beneficial. In part, this is about changing the perceptions about care and support. The contribution that social care services make to wellbeing for individuals, families and communities, and society in general, is so often taken for granted.



Leadership is about vision. But it is also about listening and involving and having the courage to take difficult decisions in making choices. Leadership in adult care and support needs to be set within a values framework, as social care leadership has many levels. And leadership in this context has to be about more than simply sharing power and control with people receiving services and carers – **fundamentally it's about the transfer of power.**

We see leadership and the specialist role of social work as a crucial linchpin to reframing adult care and support as professional activity. There is a leadership (as distinct from management) responsibility to set out clearly the steps necessary to create, implement and sustain change in the way that care and support services are shaped and operated. This is also about leadership at many levels, including at the frontline of adult care and support, as well as amongst carers and communities. The King's Fund identifies this as 'collective leadership': leadership of all, by all, for all.⁵ The key elements of collective leadership are outlined in this diagram.

It will be the exercise of leadership to turn the lessons of the past into a vision for the future. To work collaboratively to break down the barriers that work so effectively to resist changes to the status quo. This will mean challenging, and dismantling, some firmly established interests.

We agree with the view put forward by Professor Bengoa's Panel that successful transformational change depends on:

- a balanced approach between a top/down and bottom/up approach;
- people not strategies, and relationships not systems;
- change being seen and accepted as everyone's business.

In 'Systems, Not Structures' Professor Bengoa argues that the process begins with developing a vision and creating the conditions for local improvement to facilitate change. This is a view which received widespread support at our workshop on workforce issues. At the same event there was also a strong bid to recognise that leadership is present, and required, at many different levels, including political and professional, alongside service user and carers.

“ We need radical leaders willing to take risks and push through real reform. ”

WORKSHOP COMMENT

5. King's Fund - Caring to change: How compassionate leadership can stimulate innovation in health care

There is a considerable literature on professional leadership in social care to build preventative, person-centred and personalised approaches to meeting future demand, which we do not need to cover here. For example, the joint work of the Association of Directors of Adult Social Services (ADASS), Think Local, Act Personal (TLAP), the Local Government Association, Skills for Care and South Central Strategic Health Authority in England, to develop a programme of 'Leadership for Empowered and Healthy Communities'. Such literature consistently highlights the importance of values, professional capabilities and communication skills. The Expert Advisory Panel would like to see such attributes broadened in the 'community leadership' role of social workers to harness the energy and creativity of local communities, and we explore this along with the role of social work in the section on the workforce.

The Expert Advisory Panel therefore welcomes the commitment in 'Delivering Together' to develop a health and social care-wide leadership strategy. However, it is essential that alongside this the importance of leadership outside the formal health and social care system – service users, carers, communities, politicians – is fully recognised.

Steps to implementation

Implementing change will require a coordinated approach that mirrors the endeavour to keep the individual citizen at the centre of any system of support. Successful change will require partnership working which involves people receiving care and support services, their carers and communities along with professionals in the care system – both as commissioners and providers of services.

It is the view of the Expert Advisory Panel that the readiness for change seen in the submission of evidence and highlighted throughout discussions offers a hugely positive platform from which to formulate a strategy to implement transformational change. The significant benefit this could bring should not be underestimated.

Whilst progress towards new ways of arranging and delivering services rarely move in a linear fashion with a clear beginning and end, it can be greatly assisted by a recognition of the need for change and a shared understanding of the intended outcome. We are also struck by the potential benefit of making the most of the fact that Northern Ireland is of a size to bring about change to services across adult social care in ways that stimulate new models and new ways of working. **The promise of a 'revitalised' system that turns the current challenges into opportunities by making more of joining-up user-led community and formal services to act as an exemplar for positive action.**

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 (HSC) Trusts, together with other key bodies in Northern Ireland, take a specific lead in promoting the positive contribution of adult care and support.

This initiative will need to involve all the key stakeholders. It will also benefit from specific discussion with the media to inform and shape the next stage of the consultation process.

“ We need to
change hearts
and minds of
professionals so
they start to trust
service users
and carers. ”

WORKSHOP COMMENT



THE CITIZEN AT THE HEART

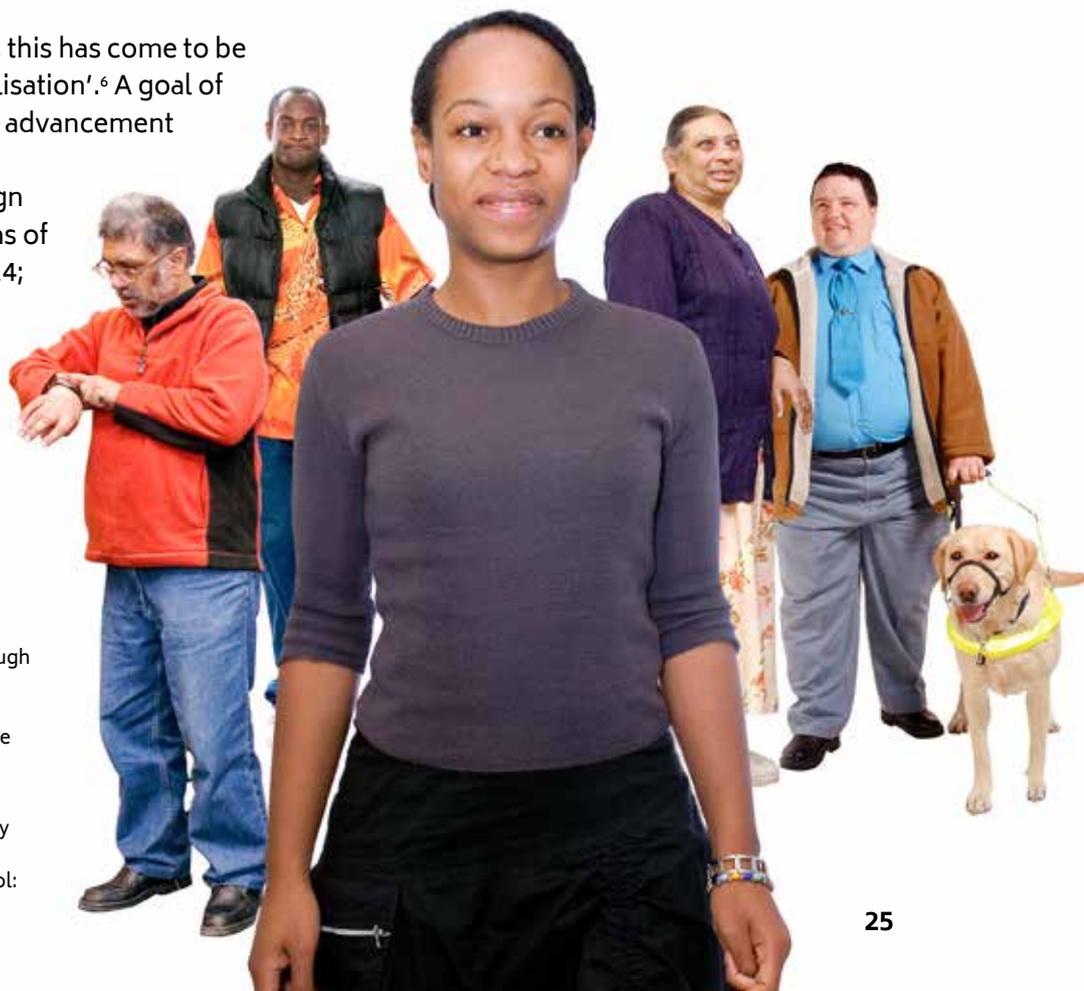
This section gives prominence to the primary tenet that the best starting point for determining a fair and equitable system of adult care and support is the individual citizen. It was identified as a major priority area in our Call for Evidence and we explore ways in which systems of self-directed support could become the norm in organising adult care and support services.

Truly person-centred – from rhetoric to reality

A renewed focus on the individual citizen is central to the concerns of this review.

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. The Expert Advisory Panel wishes to emphasise at the outset the fundamental importance of a human rights approach in which people with care and support needs enjoy the same entitlements to quality of life and wellbeing as all other citizens.

In social care circles this has come to be defined as 'personalisation'.⁶ A goal of which has been 'the advancement of citizenship' and attempts to "redesign professional systems of control"⁷ (Duffy, 2014; see also *Shaping Our Lives and Think Local Act Personal – the TLAP partnership*).



6 Carr, S. (2010) *Personalisation: A Rough Guide* (revised edn), London: Social Care Institute for Excellence

7 Duffy, S. (2014) 'After Personalisation' in C. Needham and J. Glasby (eds) *Debates in personalisation*, Bristol: Policy Press

Social care (and health) services have responded to a growing 'consumerism' in public services, alongside rising expectations, with efforts to recognise the place and value of user-involvement. But progress is patchy at best and the extent to which such involvement has yet created real and sustainable change remains an open question. Arguably the voices of people receiving care and support (as well as carers) are getting louder but whether these voices are truly being heard, let alone acted upon, is still a moot point.

The Expert Advisory Panel has been impressed by the level of work that has been done to ensure that efforts to reform the system of adult care and support are, as much as possible, 'co-produced' with people who receive services and their carers. The formation of the Adult Care and Support Reference Group, facilitated by the Patient Client Council, and efforts to ensure that their concerns and views have properly informed the work of the review has been greatly valued. We know that the recommendations of the report from Professor Bengoa were shaped by consultation with patient and user groups and, we believe, it is every bit as important to the formulation of our proposals.

In the Call for Evidence three priority areas are relevant to the theme of the Citizen at the Heart of Services:

- in Priority Area Two: '**Supporting people to regain, retain and maintain their independence**', the preference for a system valuing prevention and early intervention was noted. Growing evidence⁸ shows that intervening early can significantly reduce the need for acute services at a later stage. Social care has an important part to play in rebalancing services. However, not all care and support needs can be prevented and therefore services are required which provide appropriate support and help restore capacity and independence. Forms of intermediate care such as rehabilitation and reablement are vital and can be invaluable when offered at the right time for the individual.
- in Priority Area Three: '**Supporting carers**', attention was drawn to family changes alongside concerns that limited information and support is currently available for carers, which we will consider in the following section.
- in Priority Area Four: '**Choice and control**', the changing expectations that people have of social care services were highlighted. People are understandably unwilling to accept the offer of a limited range of established services to meet a broad range of identified needs. An outcomes focus, as defined by the individual and those close to them, is of fundamental importance. Forms of self directed support, including Direct Payments and Personal Budgets designed to unlock new services and different ways of working with better outcomes, are therefore seen as having considerable potential.

What people say they want

"A life not a care package" was a comment made at one of the workshops and it chimes with statements that seek to give meaning to wellbeing and quality of life for people receiving care and support. **Promoting independence to maximise choice and control is easy to write into a mission statement but can be more challenging in the delivery of a social care service.**

8. (2010) PSSRU - The National Evaluation of Partnerships for Older People Projects

9. Think Local Act Personal (2012) - 'Making it Real: Marking progress towards personalised, community based support'

Considerable work has been done to champion user-led initiatives to harness the transformation potential of 'personalisation' as the key to modernisation of adult social care. In England, the 'Making it Real' framework⁹ (published in 2012) developed by the Think Local Act Personal (TLAP) partnership, which includes a powerful National Co-production Advisory Group, sets out clear statements along with markers of progress. It is not a performance management tool but a way of measuring progress towards personalisation.

The framework is divided into six themes:

- Information and advice – having the information I need, when I need it;
- Active and supportive communities – keeping friends, family and place;
- Flexible and integrated support – my support, my own way;
- Workforce – my support staff;
- Risk enablement – feeling in control and safe;
- Personal Budgets and self-funding – my money.

Each of these themes is supported by accessible, practical, aspirational statements – the 'I statements'. The statements describe what people might say if personalisation was working well for them. In essence, such an approach is about enabling people to live an ordinary life and one which is not defined simply by personal care needs or the way that services are organised and delivered. The unique aspect of 'Making it Real' is the fact that provider and commissioning organisations are encouraged to publicly share the progress being made towards personalised, community-based support. Furthermore, National Voices, a coalition of charities that promote people being in control of their health and social care, have adopted the 'I Statement' approach¹⁰ as the means to set out explicitly the patient benefits that integrated care is meant to achieve.

The HSC Trusts are in the process of rolling out Self Directed Support in Northern Ireland but progress has been acknowledged to have been slow. While there was support for the concept, a number of concerns about Self Directed Support were raised with us in our Call for Evidence and through meetings and the workshops. These include the level of personal budget, limited brokerage support and perceived administrative burden. If these concerns can be addressed, we believe that models of self directed support can play a key role in ensuring that the focus of support is indeed on "a life not a care package".

Shifting emphasis away from professionals – transferring power

On many occasions in the course of this review we have sought to ensure meaningful involvement of users and carers as well as frontline care staff in the review process. This has been echoed in discussions, visits and the workshop sessions. The Expert Advisory Panel strongly support the sentiment expressed in the phrase: "nothing about us without us" (used in the 2001 White Paper 'Valuing People'¹¹).

10. National Voices (2013) A narrative for person-centred coordinated care, Leeds: NHSE

11. DH (2001) Valuing people: A new strategy for learning disability for the 21st century, London: TSO

In our meetings with the Adult Care and Support Reference Group we have sought to hold good to the principle that **successful reform of the system of adult care and support requires a genuine transfer of power** – as well as resources - and must not be undertaken as a 'top down' exercise. It will be better for being co-produced and will ensure appropriate buy-in, ownership and support. Partnerships at a local level can, and do, happen naturally. However, there is also a leadership responsibility for the HSC Trusts to facilitate local partnerships and partnership working. The earlier that users, carers and service providers are involved in such developments the better.

Personalisation, together with an emphasis on preventative services, brings a need for different service offers and, in turn, different relationships between those receiving the service, commissioners and those providing them. **This will only be possible if these relationships are truly collaborative.** Personalisation in the provision of social care should therefore 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.

For the avoidance of any doubt, we firmly support initiatives that make it possible to shift the emphasis from professionals to people receiving services, and away from acute or institutionalised services, although we are mindful that this will need to be negotiated and that some people may have additional safeguarding needs which will have to be addressed for this to be possible. In addition, decisions about services to provide support should be made as close as possible to the individual receiving care and support and offered and operated in flexible ways. Furthermore, the desirability of an outcome-based approach to the provision of social care is a fundamental principle we want to make explicit.

It is our view that the term 'outcome-based' in the social care context has become familiar before there is a proper understanding of what it actually means. The outcome to 'enhance quality of life', as outlined in the Adult Social Care Outcomes Toolkit (ASCOT) for example, is informed by domains including control, dignity, personal care, food and nutrition, safety, occupation, social participation and accommodation.¹² We are fortunate to have seen projects seeking to make a reality of outcome-based ways of working and putting this principle into practice in ways that show sufficient promise to be worthy of further investment, testing and evaluation. Services such as The Cedar Foundation's 'Inclusion Matters' and 'Inclusion Works' are good examples of a sustainable approach to social care that enables person-centred planning and promotes choice and independence.

12. "Details of the development of the Adult Social Care Outcomes Toolkit and methodology can be found on the Personal Social Services Research Unit website www.pssru.co.uk"

13. "Glasby, J and Littlechild, R (2016) Direct Payments and Personal Budgets: Putting personalisation into practice' (3rd edn) Bristol: Policy Press; see also SCIE Report 36: 'Enabling risk, ensuring safety: self-directed support and personal budgets' (2010); and the Health Foundation Evidence Scan on Personal Health Budgets, (September 2010)."

INCLUSION MATTERS

Cedar's Social and Community Networking Service supports people with disabilities living in towns, cities and rural locations across the 5 HSC Trust areas. The service aims to:

- develop and maintain effective partnerships within the local community;
- work with participants to develop individual action plans to increase their involvement in the local community;
- identify and support participants to actively engage with local social inclusion and community networking opportunities;
- support participants to identify and implement support systems which will enable them to overcome barriers to inclusion;
- motivate and empower participants to socially engage in their local community;
- promote peer support to heighten the social and community engagement of participants and the sustainability of activities.

Evaluation of the service found that it is sustainable, low cost and effective, costing around £3 per hour, and it is proving to be sustainable in the long term, with service users perceiving it as producing permanent change in their lives (based on external evaluation by Alison Wightman and Inclusion NI).

Enhancing choice and control whilst balancing risks

The concept of self directed support, including direct payments and personal budgets, has become synonymous with personalisation. Developed to enable people to receive a pot of money rather than a commissioned service, they are intended also to unlock new services and different ways of working with better outcomes as defined by the individual. There is a growing literature on different forms of self directed or 'consumer-directed care'.¹³ While Direct Payments and Personal Budgets have become familiar concepts across the countries of the U.K. (and elsewhere) there are many different variations of the model. Personal Budgets or direct funding models can now be found in many parts of the world including, for example, in France, The Netherlands, Sweden, New Zealand and Australia. Although evaluations of the impact based on international case studies are somewhat limited because of the difficulties of comparisons across different welfare systems and legislation, there appears to be a growing acceptance that models of self directed support have become a mainstream feature of social care practice. This approach was enshrined in the 2014 Care Act introduced in England, while the Scottish Government, with the support of key stakeholders, have put in place legislation, a national implementation plan and made significant investment to embed self-directed support as the approach to social care with The Social Care (Self directed Support) (Scotland) Act 2013.

Clearly self directed approaches can have considerable potential although, for a variety of reasons, models have been rather slow to develop and are yet to realise the ambitious aspirations that early pioneers had of them.

We make reference to the issue of risk at several points in this paper. It was suggested to us that there is a tendency of a **risk averse culture** around care and support in Northern Ireland. In the time we have had to undertake this review we were not able to determine whether this is true or whether the attitudes to risk held by different stakeholders in the system in Northern Ireland are any different to that found elsewhere within the UK. We have sought to understand the extent to which the attitudes to risk in Northern Ireland are different and whether concerns about risk are used unreasonably to deny services or as a reason against change. It is evident that they can have a disproportionately stifling effect on enabling people to get the support they want. Fear of blame, and the consequences, and a lack of trust may in this way contribute to restricting choice and control for individuals. We acknowledge that it is important to understand the extent of the challenge that developing a person-centred approach giving greater control to individuals receiving care and support can inevitably bring. Safeguards clearly need to be in place to protect people and avoid neglect. Rights need to be balanced by responsibilities to manage risk.

In response to our Call for Evidence one service user wrote:

"Society is increasingly risk averse. In terms of care this sometimes means that there is a focus by professionals on safety concerns, which can conflict with an individual's wish to live independently. This balance between safety and autonomy can be a difficult one to strike. I feel strongly that while safety issues should be given due consideration, they should not automatically assume paramount importance. A person's care should be considered in the broader context of social and psychological needs as well as physical safety, and service users should, of course, be involved in decisions about their care at all times."

We support the spirit of this comment 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.

There may also be a need for brokerage and advocacy to make this real for some individuals. We see an important role for social work in leading such change. In a system underpinned by a vision of person-centred and community-based intervention to support people, the primary role of adult care and support might therefore be redefined to encourage a much greater emphasis on both prevention and enablement to promote independence and enhance wellbeing.

14. World Health Organization (May 2016) Assistive technology factsheet

15. Carretero, S (2015) 'Technology-enabled services for older people living at home independently: lessons for public long-term care authorities in the EU member states'.

16. Social Research Centre and Ulster University, (2008) "Evaluation of Impact of Assistive Technology at Ardkeen and Hillmount Court Supported Living Options, Belfast"

MY LIFE PORTAL – SELF DIRECTED SUPPORT IN ABERDEEN

The SDS Team in Aberdeen has developed a simple online tool to help people source information about SDS and support services, goods and activities offered by local organisations and service providers. The My Life site allows all local providers to promote their goods, activities and services, as well as giving people easy access to the most up-to-date information on what is available in their area. This will help people make decisions on how best to spend their personal budget to meet their needs.

For more information see <https://aberdeencity.mylifeportal.co.uk/home>

In our view there is sufficient commitment to self directed support as an approach, and evidence of its effectiveness, to justify further development to put the person receiving care and support firmly in control and proliferate an expansion of the model across social care services. There is scope to further develop models of self directed support to establish new models of supporting people and new ways of working. We propose that mechanisms to stimulate such models are further developed and facilitated.

The place of technology in care and support

A wide range of factors can contribute to supporting people and enabling their independence to be protected. Housing and transport are perhaps the most obvious examples. **Technology similarly has huge potential.** So much so that it is commonplace for reports to reference the vital contribution of various forms of assistive technology, including telecare and telehealth, designed to enhance independence. Whilst the use of technology has become familiar in so many aspects of our lives, it has been somewhat slow to develop in the provision of adult social care. Work by the World Health Organisation on assistive technology¹⁴ highlights the benefits of forms of assistive technology and the problems associated with the lack of policy coordination or integration in many countries. A paper by Dr S Carretero¹⁵ includes analysis of good practice in technology-enabled services across different countries to draw out lessons and recommendations for long term care.

There has been sporadic use of new technologies in adult social care in Northern Ireland. For example, we witnessed its successful use in Meadowvale supported living settings for people with brain injuries, but such an example is far from being the norm in social care practice. Evaluations of this type of technology underline the huge potential benefits it can bring to people, vastly improving their independence and consequently their quality of life.¹⁶ But technology doesn't always have to be so complex, or expensive, as the systems used in bespoke supported living units. We have heard of a number of examples of simple, cost effective solutions making a big difference to individuals – whether that is by helping them to connect socially to others, or allowing them to be monitored in their own home rather than in a hospital bed. Often, the challenge is making these technologies more widely available, and encouraging service users and care providers to use them. Sometimes fear or accessibility can be an issue, so there is a need to both promote the benefits of using technology, and invest in information, advice and infrastructure to make adopting new technological solutions possible.

Making self directed support the norm

In this section we have placed paramount emphasis on the individual citizen at the heart of any system of adult care and support. We see this as absolutely vital to a person-centred/ relationship-centred (and community-oriented) vision of future service options. It is the view of the Expert Advisory Panel that there is sufficient evidence of the value of self directed approaches and improved outcomes to justify investing in their development and expansion. We would like to see prominence given to self directed models in order to ensure they become the initial means by which all adult care and support services are determined and provided. **We want to see individuals given greater consumer sovereignty as a means of changing commissioning for adult care and support services.**

In the sections that follow we build on this notion of the individual citizen at the heart of services to better understand needs in the context of available family support, community resources, as well as the personal commissioning of more formal social care services, such as domiciliary care and care home provision or primary health care. The foundation to the whole-system approach we are describing is the human rights we all enjoy and which should be experienced as a continuum of seamless support services.

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.

“ The social care model of the future needs to be based on promoting independence, empowering choice and enabling integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities open to everyone else. ”

ASSOCIATION FOR REAL CHANGE

“ A public awareness campaign looking at what caring is and the spectrum of carers there are is vitally important. ”

CARERS COALITION



FAMILY CARERS - VITAL PARTNERS FOR SOCIAL CARE

This section acknowledges the significant contribution made by family, friends and other informal carers to the health, wellbeing and human rights of adults with support needs as well as to the adult care and support system as a whole. Currently, they may be seen as the bedrock of care as their contribution is the primary way that most people experience care and support.

Partners in adult social care

There are nearly 214,000 informal carers in Northern Ireland. This means that almost 12% of the Northern Ireland population carries out some informal caring.¹⁷

Carers NI estimate that informal carers (aged over 16) are providing at least 2.4million hours of unpaid care every week, and suggest that, if that care was provided by a home help on the minimum wage, it could cost the government more than £16million a week in wages alone.¹⁸

40% of carers provide more than 20 hours of care per week. More than a quarter provide over 50 hours.

(Source: Census 2011)



17. Census 2011

18. Carers NI submission to Call for Evidence, referencing "Who Cares for Carers (2016) Detail Data"

The report, 'The Human Rights of Carers in Northern Ireland'¹⁹ (2014) by the Northern Ireland Human Rights Commission states:

"Caring can be rewarding and fulfilling as well as demanding. What is important is the need for recognition of the role being played and that support that should be available and easy to access. Too often, obtaining support can simply be a further additional struggle to overcome.

Carers are not a homogenous group. Carers can be all ages from children to the very elderly who are looking after family members. Each carer is an individual who has his or her own story to tell and particular needs." (p1)

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. Not just to their own nearest and dearest but often as support to others also in caring roles. 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.**

For many, although they may want to care, it can have a significant impact on their own lives. At one of our workshops a carer commented: "for some caring is a lifelong commitment". It can have a bearing on their ability to remain working or can lead to feelings of loneliness and isolation which can result in a detrimental effect on their own physical and mental health and their wellbeing. We also heard that in some instances carers feel taken for granted, they feel that it's just assumed that they will just carry on with it. It is clear that too often family carers do not feel that they are treated as partners in care and part of a team of support for an individual.

In our view we need to find a way of supporting, understanding and valuing the carers role more explicitly and honestly. **Considering the immense contribution carers make, we neglect or exploit them at our peril.** Despite the inevitable challenges that providing care and support can bring, we have been surprised at the reasonableness of the requests made by carers. 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 seen as a real part of the adult care and support system.

Many carers undoubtedly offer care willingly because of love, affection or a sense of duty to the person needing support. However, there is a great deal of evidence that even when this is the case, the inadequacies of care available to the person with care needs combined with a lack of support and attention to the rights and needs of carers, often results in a situation that is detrimental to the carer in a number of ways. The research and information briefing paper to the Northern Ireland Assembly in 2016, Carers: Legislation, Policy and Practice²⁰, draws attention to the negative impact on carers' physical and mental health; the detriment to their social integration and inclusion; the financial difficulties and loss of income many experience; difficulties in relation to work, career and education. The paper also points out that during the past two decades, across the whole of the UK, legislation has been introduced which addresses carers' rights. It is argued, however, that such legislation in

Northern Ireland has lagged behind that in the rest of the UK to the detriment of the rights and opportunities of carers.

The Human Rights Commission report referenced earlier makes a total of 15 strongly worded recommendations, including that raising awareness amongst carers of the availability of support should be a priority and takes a rights-based approach to ensuring policies and practices value the contribution of carers. Sadly, the evidence to our review suggests that little real progress has yet been made in achieving the ambitious aims of the Commission's report. It is therefore the view of the Expert Advisory Panel that new legal provisions are needed to ensure that carers in Northern Ireland at least have the rights accorded to carers in England by the Care Act 2014.²¹

The recommendations made in the report remain valid in our view, and are still required, as carers are the bedrock of our adult care and support system. **We must look at ways to strengthen their rights and to better support them.** There can be little doubt that family, or informal carers, already contribute the largest share to supporting people and this takes no account of the very many people who remain unknown to the system and who probably wouldn't actually define themselves as 'carers' or to having any specific support needs. Most care and support takes place in private. It's a personal thing and for many carers the term 'care' probably does not adequately describe what they do. Their contribution to personal wellbeing, quality of life and health is absolutely vital therefore and deserves to be fully acknowledged as an essential part of the adult care and support system and, when necessary, appropriately supported by services. They provide care and support to as wide a range of adults and children with different needs as might be defined by the term 'adult social care' - often 24 hours a day and 7 days a week. **If the regular care and support they provide was withdrawn there can be little doubt that the system of adult social care would collapse.**

Indeed Carers NI estimate that carers save the government some £4.6 bn every year.²² This reflects similar findings by Carers UK²³ which demonstrates the substantial contribution made by family carers.

Bringing a legal status to carer rights

The logic of this approach is to make explicit the rights of carers alongside rights for people receiving care and support. It is the view of the Expert Advisory Panel that the protections that form a part of the Care Act introduced in England should apply in Northern Ireland. We were concerned to be informed that there is currently no specific, binding requirement for the HSC Trusts to provide support to family carers.

19. Northern Ireland Human Rights Commission (2014) The Human Rights of Carers in Northern Ireland

20. Carers: Legislation, policy and practice (2016)

21. Care Act 2014 - <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

22. Valuing Carers 2015 – the rising value of carers' support [2015] University of Sheffield, University of Leeds and CIRCLE,

23. Carers UK Valuing Carers 2015 – the rising value of carers support

Appreciation, education and information

It is not in any way unusual for carers to lack essential information about matters that can have a significant impact on their lives. Although there is now a body of evidence to inform the emergence of carers as a policy priority and a series of initiatives designed to develop more and better support, the gains have been slow, piecemeal and hard-won.²⁴ As recently as 2016, Carers UK²⁵ was highlighting the fact that 1 in 5 (22%) of carers say they received "little or no helpful information or advice and felt they did not know where to go for support with caring." As the majority of social care and support is provided by informal carers, ignoring them or taking them for granted, may have serious consequences both for them and the people they support. Such a lack of appreciation of the contribution of carers denies the impact that it can have on their own lives: physical and mental health, the loss of social contact, being unable to work, lost opportunities for promotion or income, a finding starkly emphasised in Carers UK's report State of caring 2016.

Enabling carers to continue to offer support is essential to the future sustainability of the adult social care system. The Expert Advisory Panel supports the need for carer-friendly initiatives as articulated by Carers UK²⁶.

It is an obvious point to make that carers need to be able to have a life beyond their caring role. They may need the help of their communities and the HSC Trusts to make this possible. Through information, and education, the boundaries between social care, public health and healthcare need to be softened. All parts of the adult care and support system need to work together to establish clear and coherent 'care pathways'. Professional assessment of need should be about mapping assets rather than simply rationing access to resources. A single point of access for services was raised by carers in our discussions. The stress felt by family carers, including the understandable concerns on the part of ageing parents of adults with disabilities, remains a key theme. It is important to have awareness of the implications for those ageing without family to support them if required. This is a particular concern in Northern Ireland where there is a higher proportion of older people with a learning disability living in the family home being cared for by an ageing family carer than elsewhere in the UK and Ireland.²⁷

The Expert Advisory Panel are mindful that issues of safety and risk may be as pressing for carers as for professionals in the adult social care system. Clearly it will be necessary to fully involve carers in discussions about risk and safeguards. A focus on person-centred ways of promoting independence and the transfer of power from professionals needs to take account of the unique role of family carers.

24. See for example Clements, L (2015) Carers and their rights – the law relating to carers 4th edn, London: Carers UK and Carers UK (2016) State of Caring 2016

25. Carers UK (2016) State of Caring 2016

26. Carers UK and partners (2016) Building carer friendly communities: Research report for carers week 2016 London: Carers UK

27. Providing support to people with a learning disability transitioning into older age. NI Assembly

“ it is imperative that policy makers and commissioners in social care recognise that accessible, person-centred short breaks are in very short supply in NI. ”

POSITIVE FUTURES

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.

“ We challenge
government
to invest in
communities
to develop
innovative
projects. ”

MID AND EAST ANTRIM
AGEWELL PARTNERSHIP



BUILDING RESILIENT COMMUNITIES

In this section we consider the importance of community for adult care and support arrangements and the networks surrounding individuals. Models of best practice in developing resilient communities clearly need to be further scaled and spread.

Care and support in a changing society

The scope of our review is to consider how the system of adult care and support can be transformed in Northern Ireland to meet the needs of society in the 21st Century. So often when we think of adult care and support we focus on professional care and support services such as domiciliary care, care homes, supported living, day centres and perhaps some primary health care services. Is this really where we should start? The fact is, the majority of us will not require any of these professional care services, at any time in our lives. Age or frailty or disability does not, of itself, result in needs which require professional care services. Only a small proportion of older people, for example, currently receive a domiciliary care package or are living in a care home. Indeed, less than 7% of our over 65 population receive domiciliary care, while less than 4% are in a residential or nursing home.²⁸ This does not mean however that those without current care needs will never have a need for care and support at some point in the future.

Equally, care needs are experienced differently by everyone. Some of us require care and support throughout our lives supporting us to be as connected and as independent as we can be. Such support enables us to lead fulfilling lives. Whether we



28. Calculations based on NISRA 2015 mid-year population estimates (NISRA), Statistics on Community Care for Adults in NI 2015-2016 (DoH), and Domiciliary Care for Adults in NI 2016 (DoH)

have a learning disability, physical impairment or experience mental distress we may need varying degrees of care, changing throughout our lives. But each one of us is an individual, each has particular choices and expectations, hopes and aspirations. Too often though, when support is offered it is too generic and not personal enough for us or our families – it is not sufficiently personalised to meet our particular needs or requirements.

Of course the overwhelming majority of care and support is provided informally within families and the communities where we live. It is the nature of things that we rely on interdependence in this way to live independently.

As we outlined in section 2, the future of our changing society means that many more of us will live longer lives despite ill health or disability. Conditions previously untreatable can now be managed and younger disabled people can also expect to live longer and more fulfilled lives than previous generations. These are things to be celebrated - living longer is a good thing. However, this may mean that, in the future, many more of us will be informal carers. It seems likely that carers will always be the biggest and most essential part of any adult care and support system, as they have always been. They are the 'bedrock' of the care and support system as we discussed in the previous section.

Resilient, capable communities

Notions of community cohesion, engagement and empowerment have long featured as a strand of social work and social policy. Assisting people to come together to improve the lives of everyone in the community has similarly informed many policy initiatives. Various, efforts have been made to transfer power to communities/neighbourhoods and encourage people to play a more active part in local life or social enterprises to assume responsibility for the provision of services. Such endeavour has an important role in the development of resilient and capable communities. **After all, care and support is local.**

The Expert Advisory Panel have visited and heard of many excellent examples of neighbourhood-based networks of support during the course of this review. We have been impressed with one particular project, based in north Belfast which is Creative Local Action Responses and Engagement (CLARE). CLARE takes an asset-based approach asking: "what would you like to achieve?" and "what outcomes do you want for yourself?". They then work closely with the person to identify their assets and any existing connections. Who is important to me? What do I like doing? What makes me happy? How do I keep myself well? A feature of this approach is to have 'conversations' with people as part of a less formalised approach to assessment. This contributes to providing the means by which people can direct, and be involved with, the design of their own network of support.

The approach is one of finding out about the person and then connecting them whether that be to a voluntary group for social engagement, clinical services for health management or supporting carers and family networks. Crucially it mobilises the assets in a family and neighbourhood around the person to help them achieve what they want.

It starts with the person and their strengths (as we argued in section 2) and then makes what there is around them fit around them better. What they endeavour to resist is working in ways that make the person fit into the structures of the existing system. Crucially too, this

CLARE CIC (Creative Local Action Responses and Engagement) is a community interest company created in response to a series of community conversations, stakeholder meetings and innovative thinking from a community about how social care and health care could be designed and delivered differently. It began in Mount Vernon in north Belfast and quickly became a north Belfast wide project. CLARE accepts referrals from the Belfast HSC Trust and a small GP pilot to engage with people at an early stage of concern, in order to provide advice and address potential increased social isolation and decreasing health. They do this by the CLARE social worker meeting the service user and jointly completing an in-depth Living Plan that looks at all aspects of the person's life and seeks to help them, through the use of Community Champions and voluntary groups, to achieve desired goals.

Some of the positive outcomes achieved in the two year period of November 2014 to November 2016 include:

- 219 referrals were received across Integrated Care Teams, Allied Health Professionals, Hospitals & GP Practices;
- 144 interventions were requested to address social isolation and 142 to promote improved physical/ mental wellbeing;
- 196 connections were made to supporting organisations;
- 69 Community Champions were recruited;
- Over 1800 Hours of meaningful volunteering were delivered.

approach allows the person themselves to reciprocate. It's not just about what someone needs but about what they can give too. Evidence suggests that people, irrespective of their needs, appreciate being able to give as well as receive, and it's good for us.²⁹

CLARE is not the only community based approach we've seen or read about, for example, Living Well (Moyle)³⁰, Mid and East Antrim Agewell Partnership³¹ and Community Circles (England).³² All these models have slightly different methods, but fundamentally they all strive to move away from a 'medical model', dominated by a deficit approach to age and disability and thereby move to a more people-orientated, relationship-centred way of working. This involves looking first and foremost at what someone wants and then builds a support circle around them which enhances any networks that already exist. They all focus on the little things, that 'little bit of help'.

They also greatly enhance the importance of the social - having company, having something worthwhile to do, staying in touch with friends and interests - which are as important to our health and wellbeing as keeping hospital appointments (although they can help with that too).

29. 'A Better Life: Valuing Our Later Years', JRF (2013)

30. <https://vimeo.com/193514696>

31. <https://www.meap.co.uk/>

32. <http://community-circles.co.uk>

The Living Well scheme aims to improve prevention and resilience amongst older people with multiple long-term conditions by providing low-level support to day-to-day living and utilising asset-based resources to promote empowerment and wellbeing.

The process begins with a conversation between the person and the voluntary sector coordinator, who helps them to identify their goals and coordinate a management plan. Trained volunteers provide support to build social networks around the individual to help them become better connected to their community, be more physically and socially active and subsequently have better health outcomes. Practical support, navigation and coordination are provided in order to boost self-confidence and self-reliance, leading to reduced adult social care spend and primary/community health benefits.

The following outcomes are based on the first 325 older people on Cornwall's Living Well Programme:

- 27% reduction in A&E attendances;
- 37% reduction in non-elective admissions;
- 20% average improvement in wellbeing;
- 20% of people supported to become a volunteer;
- 8% reduction in social care costs.

This approach is now being piloted in the Moyle area.

Of course being well includes being able to access appropriate medical and professional services when needed, for example: speech therapists, occupational therapists or physiotherapy. However, people's experience of the system suggests it is often too compartmented and that people can slip below the radar until crisis occurs. 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.

Outcomes for these approaches look very promising. People report higher levels of engagement, connectedness and satisfaction. These projects demonstrate how communities and neighbourhoods, with the right connections, with the right catalyst, are ready and able to mobilise as a fundamental and significant part of an innovative care and support system.

Community approaches can also help address specific needs within groups in ways that can benefit everyone. Initiatives such as "age-friendly cities"³³ and "dementia friendly communities"³⁴ are good examples of mobilising wider communities of interests.

Belfast was the first city in Northern Ireland to join the World Health Organisation's Global Network of Age-friendly Cities.

An age-friendly city is one in which organisations work together to make sure the quality of life for people is enhanced as they age.

Belfast is part of the Healthy Ageing Strategic Partnership (HASP), which developed an Age Friendly Plan 2014-2017.

See: <http://www.belfastcity.gov.uk/community/Seniors/age-friendly-belfast.aspx>

We have also seen excellent examples of community enterprises that offer work and learning opportunities for disabled people. Acceptable Enterprise in Larne, for example, is a thriving operation consisting of a packaging and internet sales centre, café and market garden. The scheme offers a social meeting hub with employment based on a fair business model. The role of employment and volunteering can also be a part of a solution for people's needs or indeed something that they engage with; just because you need support yourself doesn't mean you can't give too.

Stimulating greater connectedness

Whilst we have acknowledged the importance of family carers as the foundation of social care, they do not work in isolation. They are part of communities and neighbourhoods. Arguably we haven't always been good at connecting up. We have witnessed excellent examples of neighbourhood-based projects which have the potential to turn the adult care and support system on its head.

The current model of social care, typified by struggling on and coping until a crisis occurs, is undoubtedly a deficit-defined model. It is highly reactive. There is a growing body of evidence, for example, that loneliness and isolation are very bad for our health.³⁵ Older people, disabled people, people with mental health problems and carers can be at risk of becoming isolated with serious impacts on their health and wellbeing. An approach that focuses strongly on early intervention and prevention would therefore be good for us, in avoiding or postponing the need for higher levels of care, and in time would also have a positive impact on the demand for acute services.

Prevention, or a focus on wellbeing, should be the primary aim of the care and support system. Despite this, our system is currently focused almost entirely on 'Failure Demand' defined as demand caused by a failure to do something or do something right for the customer. Or in other terms the failure to support carers, provide early intervention and promote prevention simply creates more demand in the high cost part of the system. It's not just about money either, it's miserable for the people concerned. The Department of Health social work strategy³⁶ Improving and Safeguarding Social Wellbeing: A Strategy for Social Work in NI 2012-2022, acknowledges this approach and the significant change that is necessary to "reflect the shift in power between those who receive services and those who provide them". The strategy describes social workers as "occupying a space between the individual and society". **A professional leadership role within communities which this review fully supports.**

33. http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf

34. http://www.dementiaaction.org.uk/joint_work/dementia_friendly_communities

35. <http://www.campaigntoendloneliness.org/threat-to-health/>

36. Improving and Safeguarding Social Wellbeing: A Strategy for Social Work in Northern Ireland 2012-2022

The Social Work Strategy describes it in the following way:

"Using community development approaches and working alongside other agencies and organisations, social workers can help to build stronger, self-reliant communities and effective working relationships that promote people's rights, challenge inequalities and improve local supports." (p38)

It would be wonderful to see this happening in all communities throughout Northern Ireland and we believe that if it was, adult care and support services would already be transformed.

From margin to mainstream

Why do these and other such initiatives seem to stay merely as 'projects' or pilots? What prevents them from spreading and becoming mainstream? Arguably the existing system is too rigid and its structures dominate the ways in which adult social care tends to be arranged and delivered. Resources - people and money - are typically sucked into doing what we've always done which means we end up dealing with yet another crisis. There is no impetus therefore to invest in a longer term plan. **We have to work out how to make a fundamental shift away from a crisis dominated system into a long-term solution focusing on prevention and early intervention in which care and support is based initially around people and their communities.**

The Expert Advisory Panel acknowledges that there will always be a need for more formalised systems of care and support, such as domiciliary care and care homes, in order to meet the needs of some people at certain times. Nevertheless we need to define much more closely what they are for and why they are being used. With a focus on low level support arguably the 'demand failure' can be stemmed and controlled. Such an approach would see greater integration of informal care and support, community connectedness and, in turn, a more focused, purposeful domiciliary care and care home provision.

Engaging with communities to enable them to mobilise their resources to help create networks of support for individuals should be seen as an important part of a range of ways of promoting independence and valuing interdependence. It also greatly increases opportunities to intervene early. And not just in terms of health needs but also in combating loneliness and in supporting carers.



In our view there are two key drivers that need to be considered to empower communities. The first concerns ways in which self directed support could effectively be used to enable demand from individuals, suitably supported, to design and create the support arrangements that best address their needs. The second is whether a mechanism is needed to put resources back into communities to help underpin any voluntary services or community assets. We believe this merits further exploration. This could be designed around a 'rebate' arrangement funded, for example, from demonstrated reductions in hospital admissions, speedy hospital discharges, reductions in missed clinical appointments and delayed or avoided care home admissions.

Local government already makes a vital contribution to creating healthy, safe, sustainable places and thriving communities, and the new duty on local councils to make arrangements for community planning could be pivotal in supporting communities to become more resilient and responsive to their citizens' needs.

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, for example through:

- Better use of local knowledge, skills and assets;
- Improving connections between services, and improving access and participation, for example, to support people to lead more independent, engaged and socially connected lives;
- Securing multi – partner focused, place based initiatives (for example, in relation to mental health, early intervention, Age Friendly communities);
- Developing a more joined up approach with a focus on community health and wellbeing.

COMMUNITY PLANNING

Community Planning aims to improve the connection between all the tiers of Government and wider society through partnership working to jointly deliver better outcomes for everyone. Community plans identify long-term priorities for improving the social, economic and environmental well-being of districts and the people who live there.

“ There needs to be a shift from reactive to preventative. ”

WORKSHOP COMMENT

Although we haven't been able to explore this concept in detail, we feel that the work being undertaken as part of 'Delivering Together' on the expansion of community development offers a tremendous opportunity to align relevant policy initiatives and build greater momentum around community resilience, co-production and capacity creation. **We would like to see the reform of adult care and support fully aligned with the community planning agenda of local councils.**

We consider in section 7 the 'market' for adult care and support services, noting that the current mechanisms have not been successful in creating or enabling a mixed economy of service provision. We reflect where the market sovereignty is and where we believe it should be. But a move to a more community-based approach to adult care and support also has a part to play. It will require a conscious bias towards promoting and developing a much broader and dynamic approach from commissioners. This may mean building into procurement procedures the means to stimulate parts of the market, such as the community and voluntary sector, that have not yet been adequately developed.

Community support will not be able to support everyone or be appropriate in all situations. Neither are we suggesting that all communities can meet every need. Some people, and some needs, will still require formal systems of intervention and professional support. However, if the keystone of a transformed adult care and support system were to be individuals empowered by their own purchasing power and supported by a navigator, then this could become the impetus for radical change.

“ Community Navigators and Information and Support Volunteers act as a bridge between existing care, community and voluntary services, to help older people access necessary information, advice, advocacy, community services and social engagement opportunities. ”

AGE NI

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.

“ We need to
make social
care a career
of choice. ”

WORKSHOP COMMENT



THE PROFESSIONAL WORKFORCE IN SOCIAL CARE

In this section we consider the issue of 'professional care'. We argue that the current system of commissioning and providing professional care and support has led to a form of exploitation which in turn impacts on quality, recruitment and retention and the overall sustainability of the workforce. Addressing the perception of adult social care as unskilled work can only be achieved by raising the status of professional care. This means setting, and paying, a professional rate for the work they do. Making the social care sector a more attractive place to work will widen the recruitment pool ensuring a skilled, capable, consistent and more effective workforce.

Adult social care – not just a job

Approximately 28,000 people in Northern Ireland are registered social care workers, with approximately 12,000 of those working in domiciliary care. The Northern Ireland Social Care Council (NISCC) estimates that 75% of the workforce is employed by the independent sector with the remaining 25% employed by the HSC Trusts. Notwithstanding ongoing issues with recruitment and retention – in England, Skills for Care³⁷ have indicated that up to 10% of existing posts in the social care sector are vacant – NISCC estimates that an additional 1,400 care workers are needed every year in Northern Ireland to meet growing demand.³⁸

Very many of those people who work in social care choose to do so because they want to 'make a difference' to people's lives – **it's not just a job.** Research undertaken in England, but which we believe has equal relevance for Northern Ireland,³⁹ surprisingly found that over 50% of the respondents



37. <https://www.nmds-sc-online.org.uk>

38. Northern Ireland Social Care Council submission to Call for Evidence

39. National Skills Academy (2012) Who Cares?

had been working in the care sector for more than 15 years and only 14% for less than 5 years. Although we know that recruitment and retention are major challenges for the social care sector, this finding does challenge the view that it might seem to be dominated by a transient workforce where workers move for a few pence on their hourly wage rate. In fact, there was a strong sense of social care as professional work, with good career progression opportunities. From this survey, it was clear that **staff working in social care felt 'unfairly maligned' due to low pay, public perceptions of care work and care workers and what is seen as a constant diet of bad news in the media.** It is compounded by the fact that there is no obvious sector champion speaking in support of care workers, and is at odds with the passion most care workers have for supporting people receiving care and support.

A changing workforce?

These negative perceptions are clearly having an impact. The State of the Adult Social Care Sector and Workforce in England 2016⁴⁰ report highlights a changing picture of the social care workforce. The workforce is growing in line with the increase in the population aged over 65. Almost 150,000 new starters to the sector were recorded in 2016. However, the turnover rate has increased to almost 30% on average, with domiciliary care workers typically featuring amongst the highest turnover rates. The turnover (or 'churn') is particularly skewed towards the newer entrants to the workforce so that much of the turnover is due to workers leaving within 12 to 24 months of joining the sector.⁴¹ The core group of workers, those who've been in the sector for some time, are ageing with an average age of 43 and over a fifth aged over 55. So an experienced workforce is being slowly replaced by a more transient cohort with lots of churn. This is a bleak picture in terms of ensuring an experienced, skilled and consistent workforce, to meet our care needs in the future. It is clear that there is a significant cohort of the labour market who would, if adequately valued and respected, actively choose to work in the social care workforce, but the sector isn't able to attract them or if it does, isn't able to retain them. It seems that precisely when we need to be building our social care workforce we are making the care sector less and less attractive.

This situation is unsustainable, given the projected demand for care and the rightful growing expectations of the kindness, skill and humanity from care workers that we expect. Care work is highly skilled. Induction and basic training does not make you a skilled and effective care worker; **experience is a career-long journey.**

We expect a lot from social care workers

Some of us, but by no means all of us, will in the course of our lives need assistance to meet care and support needs. And some of this support will require professional care workers. This could be for a multitude of reasons. It may be because of disability or frailty as a consequence of illness or ageing. It may be that our family and community are no longer able to support us, to the extent that our needs demand, or indeed we may not have family close by and able, or willing, to help. Indeed, it may be that we want to move out of the family home and live a more independent life. We may need regular help in our home or indeed we may need to

40. <https://www.nmds-sc-online.org.uk>

41. The annual workforce survey undertaken by the National Care Forum has consistently estimated that around 40% of staff leave within 12 months and close to 60% within 24 months.

move to a care home or supported living scheme to receive the necessary care and support. We would, and should, expect that the care we receive is just as good, just as kind, and just as caring as we would expect from our own kith and kin. **We expect an awful lot from our social care workforce.**

We have spoken about the need to put more priority and resources into supporting informal carers and how we need to invest in our communities too, but it is our view that there will always be a need for professional care within any care and support system. Domiciliary care, alongside care homes, will always be part of a spectrum of provision to meet people's care and support needs. It is vital therefore that there is adequate investment in the sector to ensure that the workforce is appropriately rewarded, particularly as social care workers are critical to the transformation of care. A low paid, high turnover and undervalued workforce is a poor way to ensure the quality of care we demand.

Inevitable exploitation?

If caring for the most frail and vulnerable people in society is so important, why do we treat those who do it with such scant respect and recognition? Why do we appear to value them so little? They receive amongst the lowest wages in the labour market, typically the minimum wage. We expect them to provide some of the most exquisite and intimate care to our frailest and most vulnerable fellow citizens and yet we have a system that expects that they can get someone up, out of bed, washed and dressed in 15 minutes! They are required to be kind and empathetic, patient and sympathetic, motivated and resilient, skilled and much more besides. We expect them to be able to build relationships, and to listen and respond openly and honestly. We expect them to deal with people's pain, distress, discomfort and, in some instances, to support people with end-of-life care needs.

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, suspicion and when they get things wrong we pillory them. **To put it bluntly: we 'exploit' them.** It is our view that we are at risk of colluding in a disingenuous 'group think' that makes us believe that we can expect the highest of standards whilst simultaneously saying that working in social care has no more value than other minimum wage jobs. Given that the vast majority of care workers are women, and that the majority of care is given to older people, this is a deeply sexist and ageist position to have reached.

A recent report by the Office of National Statistics⁴² which analyses suicide rates by occupation in England, points to worryingly high suicide rates amongst care workers. While we do not know the precise reasons for this apparent trend, the potential vulnerability of care workers in this respect needs to be seriously borne in mind.

It appears that a rather strange situation of parallel worlds has been created for social care. Social care in Northern Ireland is largely commissioned by the HSC Trusts from for-profit and voluntary sector providers. The independent sector now provides 100% of nursing home care, 83% of residential care and 62% of domiciliary care. But there is

42. Suicide by occupation, England: 2011 to 2015 (Office of National Statistics)
See also: <http://www.bbc.co.uk/news/uk-39560735>

still a significant proportion of care that is provided by HSC Trusts.⁴³ In the public sector, wages (and conditions) for care work are fairer, whilst in the private and voluntary sector, pay is often at minimum wage rates and service conditions have been eroded. Given that the majority of paid care work is now provided in the private and voluntary sector, there is clearly an imbalance. It also makes the divide between social care (largely provided by the independent sector) and health care (largely provided in the public sector) uneven in ways which can undermine career development and stability. It also hinders attempts at effective integration as the gulf in perceived value is so stark. Why has this situation arisen? Again there is some odd thinking. Under the guise of saying, 'we can reduce the cost of care by outsourcing to the independent sector because they are more efficient', we've actually created a commissioning model that forces providers to compete almost exclusively on price. Such that we get a 'race to the bottom'. By far the largest cost for any care provider is the cost of staff. The only way a provider can effectively keep the price of their services low is through pressing down on wages and staff costs. **And in our view there is collusion with this impoverishment in the way that care and support services are commissioned.**

Improving the status of care work

Obviously pay is important. Care workers need to be paid a decent wage, at the least the Living Wage, for the essential work they do. But, across the whole of the UK, only 91 care organisations are, as yet, accredited Living Wage employers. To put that in context, Northern Ireland alone has almost 1,000 registered providers of day, domiciliary, residential and nursing home care.

Crucially, the care sector should be raised above the bottom of the pay market to enhance its ability to attract the best people across a much wider pool than it currently does. The care sector shouldn't have to be in direct competition with supermarkets, pubs and such like for its workforce. It needs to be seen as of higher national strategic importance.

Pay though is not the only thing that needs to change.

The status of care work also needs to be improved. It is an essential, skilled and professional occupation and we need to ensure that the best people are attracted to working in it, developing their career and skills, and staying in the workforce. We have to improve their pay, but we also need an effective workforce plan. **The national registration of care workers in Northern Ireland gives an opportunity to raise the status of care work to that of a recognised profession.**

Registration in itself might not appear, at first sight, to be much but it is a vital connector of the workforce. Registered status can improve the professional regard for care workers, improve communications and information around training and development, which, in turn can inform an effective workforce development strategy. Professional registration could potentially form the basis from which to develop a membership base for a representative organisation for social care workers. Creating a professional body for social care workers may be an effective way of raising the status of care work. A body setting and maintaining professional standards requiring continuing development and training would give a

43. Systems, Not Structures: Changing Health and Social Care, Expert Panel Report, October 2016

professional voice in the design and evolution of a transforming care and support system. In this paper we argue for the need to refocus our social care system to start with the person, their families and communities. We've said that most of us will never need 'paid for' care but that for some of us paid for care will be needed and it needs to be delivered by valued, well-supported and skilled people.

The Economic benefit

Too often we categorise paying for care as a drain on resources, a pressure on budgets.

Should we not take a higher level view and start to consider the macroeconomic benefits of a better paid care workforce? It's a big workforce and is likely to get bigger as we have

noted already. Social care could provide good jobs and fulfilling long-term careers that are vital to society. If care workers were better paid and their conditions were fair, they would pay more in tax and receive less in benefits. They also spend their money, in the main, in their local economies on local goods and services. The majority of care workers live within a few miles of their workplace. The workforce is broadly geographically spread, or more accurately, where there are people, there will need to be care workers. Spending on care workers pay has an economic multiplier effect which is reasonably equally distributed across communities. For example, even a relatively small care home, say 40 beds, will have a significant payroll of around £750,000 p.a., much of which is spent in the local economy. Similar economic dynamics are true for a small domiciliary care provider. And, in some areas, a social care service may be the biggest employer and therefore an even more significant contributor to that area's economy.

Although raising the pay of the care workforce will increase costs, there are mitigations, in addition to the macroeconomic benefits indicated above. A sector more able to recruit, and crucially, retain its workforce, will see savings in recruitment cost, induction training and evidence from organisations that have increased their pay offer have shown a decrease in absence and agency staff costs.

A recent analysis by the Ulster University suggests that the adult social care sector:

- Supports 41,000 jobs directly (not including Personal Assistants employed with Direct Payments) with Gross Value Added of £332m;
- An additional 30,657 jobs are indirectly supported (e.g. through the supply chain) with a GVA of £247m; and
- The sector impacts on a further 30,038 jobs through the purchase of goods and services by those directly or indirectly employed in the sector.

Source: 'Assessing the Economic Value of the Adult Social Care Sector in NI', Ulster University Economic Policy Centre

In 2013, the Joseph Rowntree Foundation became the first care provider in the UK to pay the Living Wage. Staff turnover fell by 50% in the first year.

Source: 'Why we became a living wage employer', Rafferty, S.

RAGLAN PROJECT, MONMOUTHSHIRE

- The Raglan Project is a pilot project looking at how to deliver a high standard of relationship-based home care to people with dementia;
- Staff are given freedom to decide for themselves how the relationship and care should be managed, with decisions supported rather than controlled by management;
- Evidence suggests this approach results in better outcomes both for service users and staff who have higher morale, health, wellbeing and job satisfaction.

WELLBEING TEAMS

- Based on Dutch Buurtzorg model;
- Focuses on creating small, neighbourhood self-managed teams including community circle connectors to promote independence;
- Staff experience is improved through small teams, paid at or above the National Living Wage, supported by coaches who focus on fostering reliability, kindness, trust and creativity;
- This approach is affordable through reduced layers of hierarchy made possible by the self managed approach.

CARE AND SHARE ASSOCIATES (CASA)

- CASA was established in 2004 as an employee-owned provider of domiciliary care;
- This approach taps into people's natural creativity and commitment, by giving them a stake in the business;
- Built on a culture of positive long-term impact, both on the business and across the wider community. This unique approach can be seen in practice in a number of ways, from creating a Social Care Academy, the employment of employee engagement leads, and the 'voice' employees have in its governance structure;
- CASA believes that, because employees are also the owners, they achieve the highest quality care and low staff turnover, making the business more successful.

Getting the most from the skills and capacity of the care workforce

The current model of professional care arguably does not maximise the potential of the workforce. It is highly managed and bureaucratic. Low paid staff race around to get to 15 minute visits having to 'clock on' and 'off'. It is very task-based and highly impersonal. A recent commentator⁴⁴ said that the business model of the domiciliary care sector seems more akin to a parcel delivery service than a model designed to create kindness, relationships and give good care. It is the view of the Expert Advisory Panel that commissioners need to be more creative in their thinking and learn from innovative approaches elsewhere such as those outlined opposite.

This kind of self-directed management approach has the potential to improve people's lives, empower staff and reduce costs. Introducing a more human and relationship-centred ethos into social care would be the antidote to the current managerial, vertical and industrial ethos which seems so often to be dominant in the care sector.

Leadership throughout the workforce - freeing the potential

Nurturing leadership throughout the professional care system is essential. If transformation of adult care and support in Northern Ireland is to be successful, then leadership at all levels requires nourishment and permissions. New models of care are likely to require flatter structures and a deliberate move away from a command-and-control management style. In our view, they also need the right people, appropriately rewarded, supported and with a sense of being valued and listened to.

Quality in social care is a function of the people who engage in it, not the structures designed to contain it. The structures impose significant administrative and bureaucratic burdens on managers and care workers. Not only do the structures take up their time, but they also distract their priorities. They take them away from the relationships they are trying to build simply to feed the system's demands. A report commissioned by the Joseph Rowntree Foundation in 2014 highlighted how excessive paperwork demands impact negatively on priorities and relationships.⁴⁵ Although the work focused on care homes, the same issues apply to all parts of the care and support system.

As we have noted elsewhere in this report, social care is broad and, as a consequence, so is the workforce. The care and support sector includes care workers and a wide range of other support staff, often with an equally wide range of job titles. However, there are very many other occupations employed within the care sector: social workers, nurses and occupational therapists, to name a few. Leaders, or as more often referred to in social care, managers, are the cornerstone of quality care and support. **The single biggest factor in the quality of a care service or care home is the quality of its manager.** The leaders in social care also need to be supported better too. We received evidence from My Home Life NI on a programme of supportive development that helps leaders in care settings to negotiate the complex, and often conflicting, emotional stresses of their work. Helping them to gather perspective, seek solutions and protect themselves from the very real risk of burnout.

44. Interview with Geoff Mark: <https://soundcloud.com/helensanderson/conversations-with-commissioners>

45. <https://www.jrf.org.uk/report/excessive-paperwork-care-homes-undermining-care-older-people>

Back to the future

In the view of the Expert Advisory Panel the social care workforce has been neglected and exploited. Furthermore, we believe that an effective and sustainable social care workforce strategy is an essential part of the transformation of adult care and support services. The workforce should be redefined as one of primary strategic importance, not just to the care sector in Northern Ireland, but to the whole economy and wellbeing of society.

Our proposals suggest that the workforce be 'consolidated' as a professional workforce for social care in Northern Ireland. We propose that a movement towards equalisation of pay and conditions across the care sector should be pursued. Common induction standards should be developed and a national training and development programme put in place. The aim, to create a national professional workforce with equal status and professional standards across all parts of the professional care market. A workforce that can attract the right people in the future and offer a fulfilling and rewarding career. **Such a workforce would drive up standards, enable truly citizen-led approaches and help raise the status of social care generally.**

The aim of the transformation of adult care and support in Northern Ireland should be to focus on community-based prevention maximising the wellbeing of citizens, with citizens in control. Professional paid care and support will continue to have a vital place, but in a broader, and more diverse, market of care provision. We envisage an important leadership role for social workers in communities. And social care would have the primary purpose of providing care and support to those whose needs cannot be met in other ways, or when specialist skills are required. When we do need professional social care, it is absolutely vital that a suitably skilled, competent, motivated, supported and valued paid workforce is available to provide it. And to be sustainable that the leadership within the social care sector – at every level – is similarly skilled and confident.

“ The quality and sustainability of services must be enhanced through providing adequate terms and conditions of employment. ”

UNISON

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

In this section we pose the questions: What is the purpose of social care? How should the market for professional social care be managed? And finally: How can consumer sovereignty be used to extend and diversify the whole social care market?

The purpose of social care

During the course of our evidence gathering and talking to people, a question keeps recurring. 'What is social care for? What do we want it to do?' Which then leads to the question 'Is it currently doing what we want and need it to do?' The answer to this question has invariably been a resounding no. The current 'market' of adult care and support is widely considered to be broken and no longer fit for purpose, it is failing to deliver for us and falls short in so many ways.

As we argued in section 2, social care is, and should be, very broad. But there is a tendency for it to be defined narrowly as domiciliary care or care homes - professional social care as we've come to term it. Shouldn't care and support really be seen as much wider? Surely it should include the network most of us have around us which enables us to have a good quality of life despite our need for care and support? This requires us to be able to access a wide variety of services and support, not just for physical care but also for emotional, intellectual and social needs.

Much of the formal social care provision has changed very little in the last 25 years with domiciliary care and care homes continuing to be most people's experience of care and support. Standards have developed of course and the type of provider has changed as there has been a significant shift from the statutory to the private sector. However most of the care services are much the same services as they have always been.

Why is that? Why, if the population's needs, expectations and aspirations have changed so much, is the so-called



'market' for social care still offering the same services and doing much the same things? If the media was run in this way, we might still be watching the same three channels on a black and white analogue TV!

Creating a sustainable market for social care

We have argued in other parts of this paper for interpretations of adult care and support to be expanded into a much wider, broader, community-centred and asset-based approach to individuals and their support networks. One in which prevention and wellbeing are the primary focus, together with reablement and the promotion of independence. We do believe, however, that there will always be a need for paid professional care and support services.

So what is the purpose of professional social care? We are arguing that social care, in terms of paid professional care and support, supplements that which might otherwise be offered by family, friends or through a network of community support. Social care is likely to be provided by registered and regulated care providers.

In the view of the Expert Advisory Panel professional social care will always be a part of the adult care and support system. However, the Panel also believes that it must be of good quality, well-supported and viable. In earlier sections we have made the case for widening and broadening what we mean by social care, by putting the citizen at the heart and by empowering and enabling communities. We have also argued that **good professional social care cannot be achieved through a minimum wage workforce afforded little status** and built on a business model unsuited to endeavour based on personal relationships.

Our proposals will make professional social care more expensive. However, we believe that the combination of measures we have outlined in this paper, in which wider opportunities and services would become available, mean that limited resources would be more effectively utilised within the whole social care system.

What is the social care market for and what is it intended to deliver? The system of purchaser and provider heralded by the changes to community care more than 25 years ago sought to introduce competition around quality and price. This was intended to result in consumer choice, in other words a choice of services and provider. In reality there isn't one 'market' as such. More often it is effectively a collection of smaller markets based on geography. When people need professional social care it is often at a point of crisis, a distress purchase because existing support cannot be continued or can no longer cope. But if you live in Dungannon would you scour the whole market for a care home? Or a domiciliary provider? No, you want the local care home to be a good standard so you can be near your family and friends. We don't really want to be shopping around for the best care home. We actually want our local care home (or domiciliary care provider) to be consistently good and all of the time. We also don't want it to be so fragile that it is a good standard today but not so six months later. It's an obvious point, but care and support is not the same as the restaurant market. You can't easily move to another care home or swap your domiciliary provider. Which begs the question is a model of a competitive market actually appropriate to social care?

Is it really a 'market' in the conventional sense? Is it consumer-led? The language used around social care is enlightening. We tend to talk of 'service users' rather than 'customers' or 'clients'. There are 'commissioners' rather than 'agents' or 'brokers'. This is not the language of market power being with the consumer or customer. In Northern Ireland a substantial majority of professional care and support is funded by the HSC Trusts with a significantly smaller proportion of people paying for their own care. This means, effectively, that many care providers see themselves as having only one customer: the Trusts. Not a monopoly but a monopsony. At least most of the time because once demand outstrips supply then the tables can turn and up and down we go!

Over and over the Expert Advisory Panel has heard the same concerns and they come from all sides – providers, commissioners and crucially from people themselves. The most common concerns were:

- There is very **little choice**. It's either domiciliary care or a care home and in some places the market has so failed that there isn't a willing provider to give a service.
- The market can be **unresponsive to individual needs** and wants. There is a failure to acknowledge that everyone is different with different needs and different situation.
- Some **relationships in the system are experienced as adversarial** or competitive. People don't find this helpful. Commissioning a service from a provider, issuing a contract and a service specification and then walking away isn't helpful.

The culture around care and support services needs to be one of everyone's 'skin in the game', appreciative enquiry and mutual support. It shouldn't be that each part is just thinking in terms of its own activity or budget but also what can it do to make some other part of the system work better. All parts engaged in care and support should therefore be aligned and we consider this issue in section 8.

The market as it stands only appears to have one actual competitive dynamic: the squeeze on cost. And providers compete almost entirely on price. This has led to a professional social care provision based on minimum wages, poor working conditions and financially fragile providers. This is not the context in which to expect to encourage confident, skilled, safe and kind professional care and support to be everyone's experience every time.

And what of quality?

We heard from the regulator (The Regulation and Quality Improvement Authority - RQIA) and from individuals about the sense of quality in the professional social care sector. Responses from individuals were mixed, some having positive experiences and some less so. RQIA reported on variability but not a significant difference between independent and statutory care provision. RQIA haven't adopted the ratings approach as in England. Their view is that the aim of the whole system is to ensure that all care is good and that, whilst poor standards of care must be challenged, their experience is that, in the main, providers work positively and openly with them to improve services when they are failing. The underlying causes of poor care are often, but not always, exacerbated by inadequate resources and or severe difficulties in recruiting adequate numbers of suitable staff. This is an issue that we would hope to improve with the proposals made on pay rates, workforce development and a more open and honest commissioning model. 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 needs to be sufficiently robust too.

Capacity and planning in professional social care

We have heard that the demand and supply of professional care and support services are not well aligned. Some parts of Northern Ireland are well supplied whilst other have a significant shortfall of supply. Both situations bring problems. If there is over supply, then price competition creates a 'race to the bottom', with consequences for quality and longer-term sustainability. Where there is under supply, providers can use their power to drive up prices, thereby holding the customer to ransom. In either scenario people can't access the services they need, when they need it and at the quality they require. There is no mechanism for the planning of supply. It appears crucial to us that there is a capacity strategy that uses data on projected demand to inform and implement the planning of the supply of professional social care services. Leaving supply simply to the vagaries of the market creates uncertainties, leading to market power imbalances with consequent regular local demand and supply crises. Added to which continuing to commission the same services perpetuates an imperfect market, with little scope for innovation or the development of new models or different ways of working.

A sustainable and functional professional social care market

There is a lack of honesty and transparency created by an arms-length commissioning system which is unsuited for the imperfect market that exists in care and support services. It is not the same as procuring stationery or roads maintenance. Care and support involves supporting a human environment and culture that encourages relationships and kindness. The market we create needs to recognise this. Commissioners and providers should be honest about the true costs of care and agree a funding tariff that sustains a properly paid and valued workforce, one that underpins a quality and professional sector. Recognition also needs to be made of the need for a sustainable return, whether to a private provider or a voluntary one. The responsibility is on both sides. Commissioners and providers both need to be honest about costs and transparent about priorities. In our view the care sector is not the right place for a 'profit maximisation' business model, rather a 'profit with purpose' approach.

“ It is our strongly held view that treating people as equal citizens means that they should assume responsibilities for their support, including the funding for same. ”

Adult care and support is not free at the point of delivery, unlike the NHS. **In our view the current charging arrangements in Northern Ireland are unfair and create unintended consequences.** It does not feel equitable that, if you need the support of a care home, and have sufficient funds, you have to pay the whole cost, whilst someone with the same assets and income can receive domiciliary care for no cost. In the end there is an 'opportunity cost' for every Pound spent by the State. The 'opportunity cost' is what you can't now pay for because you've spent it on something else. By giving free domiciliary care to people who could afford to contribute simply means you have less available for those who can't or to invest in new services.

The Expert Advisory Panel proposes that three mechanisms are considered:

1. **Establish a 'true rate for care'**. The finances of a domiciliary care agency or care home are not unduly complex. It should be straightforward, with the required degree of openness and honesty, to agree a true rate which recognises the need for a properly paid and valued workforce and a sustainable return for the purposes of investment.
2. 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 services, including care homes and domiciliary care.
3. **Establish a market regulation mechanism** with a market oversight role for RQIA to ensure that, in return for a 'fair price', the Living Wage is paid to staff, there is investment in quality and that excess profit is not taken. This could take the form of a market regulator, able to scrutinise procurement arrangements, fees, charges and profits for care provision or extending the remit of RQIA to include market oversight as exists for larger care providers for the Care Quality Commission in England.⁴⁶

This should allow the commissioners to be able to demonstrate adequate resources are being provided to ensure that quality can be delivered and that they are receiving value for money. The citizen would receive financial assistance in accordance with their identified needs and according to their ability to contribute. It would also allow good providers to be able to deliver the quality expected of them and to make a reasonable return on their investment.

During the course of this review the question has frequently been raised with us in relation to the current balance of private (for-profit), statutory or voluntary (not-for-profit) care providers. Concerns were expressed as to the lack of a mixed economy of care provision as evidenced, for example, by 100% of nursing homes now being in the private sector. It is our view that the current market mechanism of relying only on price has been the primary cause of this imbalance. A more open and honest market management, as we've described above, would, we believe, allow a range of providers to come into the market. A concentration on any one type of provider, or business model, will create the sort of imbalance that is now evident in Northern Ireland with potentially negative unintended consequences.

46. www.cqc.org.uk/guidance-providers/market-oversight-corporate-providers/market-oversight

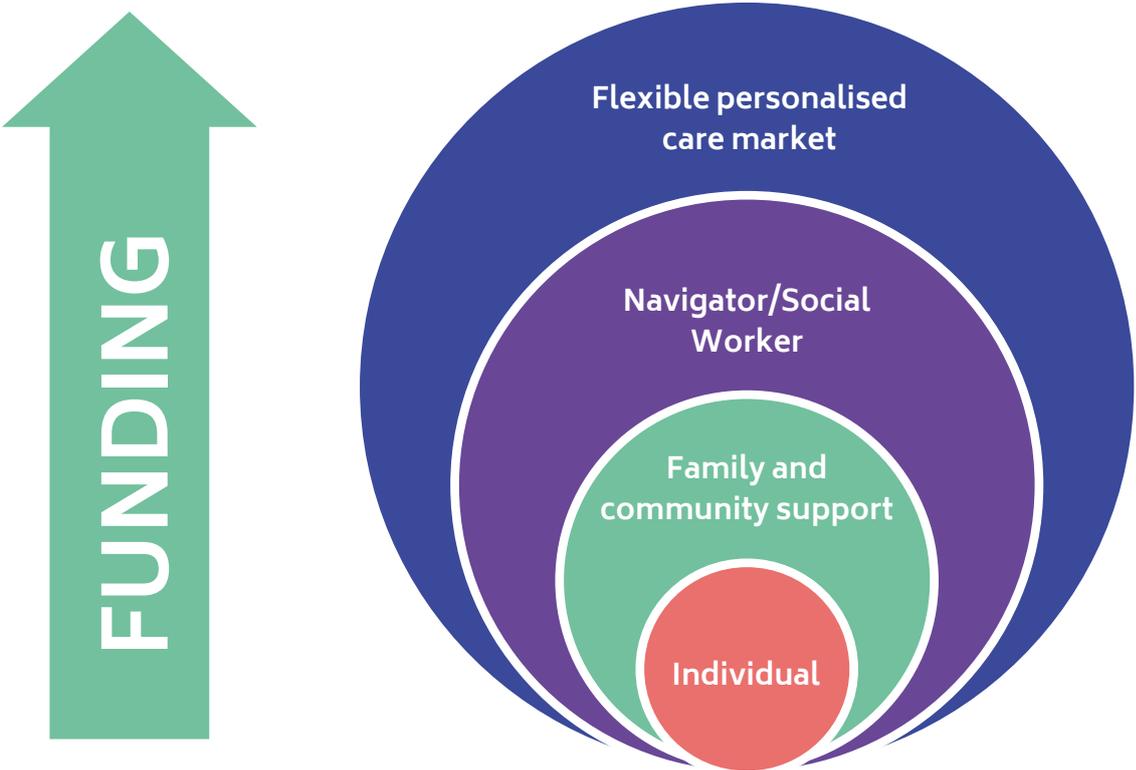
As part of the transformation of adult care and support a conscious bias is required to draw voluntary, community and social enterprise providers into a broader and more diverse social care system. Consideration of different business models such as cooperatives as well as different funding models, for example social investment finance, may be helpful.

Injecting diversity into the market

Arguably market power is in the wrong place. The adult care and support system tends to operate with 'commissioner sovereignty', sometimes 'provider sovereignty' but rarely with true 'consumer sovereignty'. This makes for different relationship dynamics between the people receiving the service and their families, those providing care and support and the commissioner of the service than is usual in other service sectors. 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 that can currently be accessed flexibly and individually at a community level.

SOCIAL IMPACT BONDS

Social Impact Bonds are a way of funding new innovative services: Investors agree to provide money upfront for a new service, and get paid back a premium if and when a set of agreed outcomes are delivered. In this way social impact bonds can enable both value for money and improved services.



The system should start with the person, together with family and community assets, supported by a navigator/empowerer/social worker (see section 5). This can help create a flexible and personalised social care market by giving the individual the knowledge of the services best suited to meeting their needs. But they will need the power too, including the money to spend, either on quality professional care services or indeed on whatever they need to maintain their wellbeing as they define it.

Taking a truly rights based approach means that, because each individual experiences their challenges differently and has different circumstances and relationships, they are the ones who are best placed to direct their care and support. In order to stimulate a diverse and responsive market in care and support services, the consumer needs to have both knowledge in terms of their own needs and information about what is available. They also need to have control of the spending power.

We have heard concerns in relation to the risks posed by this kind of approach. The creation of a community support system based on navigators would enable people to use their consumer power effectively in meeting their needs as defined by themselves. The evidence presented to us, and the discussions we have had, has drawn attention to a view that attitudes to risk can often stifle and restrict people's choices. **Such an approach to risk fails to encourage people to be involved in defining risk for themselves.**

The allocation of money should be based on a measure of outcomes and not simply the cost of specific services, in other words an hour a day of domiciliary care defined from an assessment of deficit. The notion of outcomes came up quite a lot in our discussions.

Clearly a SMART method of establishing desired outcomes and measuring progress is required. We therefore welcome and support the incorporation of the ASCOT tool within the roll out of Self Directed Support in Northern Ireland. In capturing information about an individual's social care related quality of life, it will enable the evaluation of service user and carer outcomes.

In this section we have considered using Self Directed Support as the primary default method of creating effective demand to shape the market. We've also spoken of how commissioning by HSC Trusts should change. We know that this will raise questions. To be clear, we see the Commissioner and State role as one of establishing true cost for care in domiciliary care, care homes, and so on, so they are transparent and sustainable. This would be overseen by a market regulator to ensure providers adhere to the principles of the pricing model - **a level playing field**. The consumer can then have confidence that they are getting a fair price. It may be in some circumstance that the HSC Trusts do need to directly commission some services for some types of service or for certain people as a self-directed support model becomes established and effective.

"We must agree a new risk paradigm; one which recognises and embraces the need for positive risk-taking and learns from mistakes, rather than points a finger of blame"

POSITIVE FUTURES

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.

“ Make every
contact count –
focus on early
intervention
and prevention. ”

WORKSHOP COMMENT



SYSTEM ALIGNMENT - MAKING INTEGRATION MEANINGFUL

Fragmented arrangements are a common feature of adult social care services as it relates to health, housing and other disciplines and has long been seen as problematic. This section is concerned with the joining up of services in a seamless way to maximise the effectiveness of the system as a whole, and improve the experience of individuals receiving care and support.

Integrated structures but not integrated systems?

The word "integration" has come up time and time again in response to our Call for Evidence and in our discussions. The Expert Advisory Panel have been told by many that Northern Ireland, through the HSC Trusts, has an integrated health and social care system. Clearly there is an integrated structure. The question is whether the structure results in closer partnership working that really brings a joined-up experience to those that use the system. It has been suggested to us that, despite the integrated structure, a lack of connectivity still exists and continues to bedevil the system. Integration does not appear to be working for people in need.



In particular, concerns focused on the impact of working in silos:

- Everyone is doing the job they have been asked to do but **at arms-length from the rest of the system;**
- There are **too many points of contact** with too many gatekeepers for referral. This means people often have their needs managed 'in parts' e.g. GP is managing medication, nurse is managing dressings, social worker overseeing care package, with no one place/person/provider looking at the whole picture;
- People don't receive the **right service or expertise at the right time** to get the best outcome;
- Barriers to a more aligned approach are created by such **factors as attitudes, budgets and professional status**. The structures behind services define how they are delivered, not the individuals in need.

Somehow we need to align everyone to work together in the same endeavour. How health and social care services can work seamlessly together has therefore been a recurring theme during this review. It has been said more than once to us that it's as if health and care are different countries - they share a willingness and desire to work together for the best, but they have different languages, different cultures and a different set of ideas as to what they are trying to achieve. Discussion about integrating health and care (and, more recently, housing) has been going on for years and yet it stubbornly refuses to be a reality for many of those at the receiving end of services. Thus the structural integration of health and social care in Northern Ireland does not appear to be delivering an integrated experience for people. It might be said: 'they may live in the same house, but it is definitely separate bedrooms'.

Barriers to alignment

Another issue which arose in our discussions was that of wariness and even mistrust between parts of the care and support system. This is potentially a significant barrier to greater alignment. It seems to be particularly true between the statutory and independent sector. In our view, the suspicion that profit is the only motive for some care providers hinders close and effective working between the HSC Trusts and independent care operators. Perceptions of a lack of mutual esteem can undermine relations between health and social care. These attitudes fetter open and honest working which can be detrimental to the system working well. **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.**

One of the major causes of the current demand crisis in acute health is the failure to successfully negotiate the interface of frail older people with acute hospital care. Too many present at Emergency Departments when it isn't the best solution or could have been prevented. As a consequence, too many people lose function in hospital (even after only a few days) making it even more difficult to appropriately discharge them. Too many people end up in hospital to die.

Whilst doctors and consultants may wish to consider the whole person, the structure of a hospital doesn't enable them to address the entirety of a person's needs. The same is often true for GPs. Ten minute appointments may be sufficient for diagnosing a condition

or making a referral but are unlikely to be adequate for a meaningful conversation about an individual's circumstances and their specific needs. We believe the situation could be significantly improved by considering some key relationships. The illustrations below are not exhaustive but we hope that they will give a flavour of the kinds of changes to how the system could work which may address the crucial issue of effective interfaces for integration.

SOCIAL PRESCRIBING

A Social Prescribing model is being piloted in the Western HSC Trust area. This model is provided by Bogside & Brandywell Healthy Living Centre who have employed a member of staff to act as a dedicated link to connect case work and navigate older people who are picked up through a screening process in local GP practices. Those suffering with anxiety related mental health problems, loneliness, long term health conditions with related debility and social isolation are supported to access a range of programmes aimed at improving their health and wellbeing.

Source: WHSCT response to Call for Evidence

Healthy communities

Primary care is perhaps inevitably the entry point into the health and care system for most people. It is relevant therefore to considerations about the future of adult care and support and strategic priorities. Ensuring people stay fit and healthy for longer requires a programme to promote prevention and early intervention initiatives alongside community planning to address health inequalities. Such imperatives appear to be emerging as collective aspirations for the system.⁴⁷

Our references to the provision of primary care are necessarily cursory, although we are clear that they are fundamental to understanding ways to improve the alignment of care and health systems. The first point of call for a person experiencing difficulties with their health and wellbeing is likely to be their GP. If GPs were connected into a community navigator scheme (see section 5) then the options available to them would be greatly enhanced. This would give GPs a much bigger 'prescription pad' enabling them to refer to community connectors on issues like loneliness and isolation.

The implications of closer integration between care and health is evident in many different ways. An example is that of the points at which primary care and care homes relate to each other. We were informed that the care provider Four Seasons Health Care had completed analysis of admissions to hospital via 999 calls from its care homes in the last quarter of 2016. Of the 247 episodes, 40% were related to an undiagnosed and generally unwell category where medical practitioners were unavailable or declined to see their patient, directing care home staff to call 999. In their submission to us Four Seasons suggest a comprehensive review of primary medical care services to care homes is required.

47. See: Northern Ireland Confederation for Health and Social Care 'One Voice – Time for Change' (May 2016)

Hospitals, care homes and domiciliary care

Obviously care homes (including nursing homes) are not hospitals and neither they should be. Care homes are where people live, and in the best ones people can live well despite complex needs. They can offer a certain amount of medical management and nursing care to support people with considerable needs and frailty, but they have neither the confidence nor the skills and knowledge to do it well without significant medical support.

Hospitals are not places where people live. They are where we go to be fixed. They can do a certain amount of 'social care' but they have neither the design or the resources to do it well. It is the view of the Expert Advisory Panel that the relationship between hospitals and care homes should be much closer and mutually supportive. Ideally, each hospital should view the care homes on their patch as extensions of themselves, though not the same as themselves. Closer working relations could reduce admissions from care home to hospital but also create smooth pathways for quicker effective discharge. Closer working and planning together, for example at end-of-life, could bring more of the strengths and expertise of the hospital to the care home and vice versa. Offering a better experience for individuals and reducing stress and pressure on the system as a whole.

Frail older people need a different pathway through hospital. All too often they arrive in hospital and their existing care and support (whether it be from a care home or domiciliary care) vanishes. A way of extending social care into the hospital should be enabled to improve people's experience and to speed their transition back home – whether that is their own home or in a care home setting.

If hospitals and the care homes in the same locality or community designed together, with say ambulance services, alternative pathways could be created to reduce unplanned admissions from both care homes and the community. 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. But not if they continue to be held at arm's length.

However, **we don't believe you can just commission intermediate care, you have to co-create it.** Research carried out in Kent County Council⁴⁸ showed that, of older people placed in standard residential care beds on a short term basis, around 80% remained there for the rest of their lives. When people with similar needs were placed in an intermediate care bed where there was a focus on helping people's recovery, over 80% returned home. "It was not the assessed needs that made the difference but the offer that was available to the patients at the point of discharge".⁴⁹

This approach requires a real commitment to working together, on a daily basis, knowing each other's pressures and strengths, working as a whole system, not just a collection of separate parts. You may, for example, have an excellent hospital close to an excellent care home, but if the interface between them isn't excellent then huge potential is unrealised. Some examples are outlined on the next page:

48. <http://www.local.gov.uk/documents/10180/11779/LGA+Adult+Social+Care+Efficiency+Programme>

49. "Six Steps to Managing Demand in Adult Social Care – A Performance Management Approach", John Bolton and Philip Provenzano, March 2017

WCS CASTLE BROOK

South Warwickshire NHS Foundation Trust now works with WCS Care in its Castle Brook Care Home. Having provided a therapy-led care model in a dedicated unit at Warwick hospital, the Trust recognised that patients would benefit if they received care in an out of hospital environment. The aim of the new service, delivered in Castle Brook, is to provide patients with additional short term support and therapy that will help them return home from hospital as independently as possible.

Source: <http://www.swft.nhs.uk/news/additional-therapy-help-patients-return-home>

WINDSOR CARE HOME & INTERMEDIATE CARE CENTRE (FOUR SEASONS HEALTH CARE)

This is a 39 bedded home in South Belfast, located centrally between 3 main acute hospitals and a multidisciplinary allied healthcare professional hub. This home had a falling number of services user numbers in the frail elderly category, which was less than half of its budgeted occupancy. This reduction in occupancy created the capacity to develop a new Intermediate Unit for a new service of discharge assessment beds. Using Four Seasons Health Care Intermediate Care Framework a review was conducted of the physical environment, styling, staffing levels and training requirements. Staffing levels in the Intermediate Unit were enhanced and are supported by a clinical lead post to quality assure care delivery, and provides a daily link to the Belfast HSC Trust staff. The rehabilitation care delivery is supported by a full multidisciplinary team of care managers, social workers, physiotherapists, occupational therapists and rehab assistants. There is medical cover supplied by a daily GP visit and consultant screening at the point of hospital referral. In the first 5 weeks there were 15 admissions which meant that the unit was fully occupied, with no readmissions to hospital.

Source: Four Seasons Health Care - submission to Call for Evidence

“ There is a need to advance models of integrated care (social and health) such as co-located multi-disciplinary teams that act as professional hubs... The interface between professions and improved communication pathways lead to enhanced outcomes for the individual. ”

ENHANCED HEALTH IN CARE HOMES

NHS England have identified a number of interventions that the health system could do to support care homes, which in turn helps care homes to support hospitals. Across England, six vanguards are working to improve the quality of life, healthcare and planning for people living in care homes. Within these six vanguard areas, care homes are working closely with the NHS, local authorities, the voluntary sector, carers and families to optimise the health of their residents.

'The Framework for Enhanced Health in Care Homes (EHCH) - Sept 2016' outlines what the whole system can do to help:

- Enhanced Primary Care Input
 - Individual health professional assigned to each care home. e.g. GP, prescribing nurse:
 - Regular expert medication reviews;
 - Hydration and nutrition support;
 - Out of hours emergency video link;
- One point of access for MDT support e.g. OT's, Speech Therapy etc;
- Reablement and rehabilitation;
- End of life and dementia care;
- Joined up commissioning and collaboration between health and social care;
- Workforce:
 - Joint training and supervision;
 - Joint workforce planning;
- Data, IT and technology.

For further information see: <https://www.england.nhs.uk/ourwork/new-care-models/vanguards/care-models/care-homes-sites/>

An example of one of NHS England 'Enhanced Health in Care Homes' vanguard sites is a 24 hour video link between care homes and Airedale Hospital in Keighley, Yorkshire. The care home can access directly a team of triage nurses located in the hospital. The service enables care staff to receive immediate advice and support. The care homes have reported an increase in confidence and particularly feel much more supported in terms of decision making and accessing emergency services.⁵⁰

Effective and accessible Multi-Disciplinary Teams (MDTs)

We heard evidence from a number of professional bodies representing health specialties lamenting that their skills and expertise aren't being maximised, often because the needs of the person were not being matched to the specialty. Evidence was given of 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' MDTs aligned to neighbourhoods and strongly connected to GPs and Community Navigators. For

example, there is evidence of the effectiveness of interventions by speech and language therapy in the prevention of aspiration pneumonia in the older population, which, if untreated, causes high hospitalisation rates, serious morbidity and often death (Welte et al 2012).⁵¹

Lack of alignment for those in transition between programmes of care

The lack of alignment for people in transition between programmes of care and support came up time and again in our discussions and visits. We heard the concern often and in different contexts. The frustration felt when a person is categorised according to who they are and not according to their needs. People find this hard to understand and it definitely feels like it is done to 'align' with structures, especially budgets, and not appropriately for need. Examples included when a person with learning disability reaches a certain age and is transferred to 'older people's services' when their needs relate to their learning disability rather than their age. Or a disabled child moving from children's services to adult services. We had strong representations that transitions need to be planned and overlapping for a time; "feathered" so that there are no hard cut-offs.

"The Royal College of Speech and Language Therapists consider that full multidisciplinary community based respiratory management services urgently need to be configured.... SLTs could make a significant contribution to self management of conditions and appropriate diagnosis, for example, working alongside nursing colleagues in elderly community care teams could significantly reduce the number of hospital admissions and improve wellbeing, leading to greater independence".

Source: RCSLT response to Call for Evidence

Housing and social care

Despite the fact that during our visits we saw some excellent examples of housing based support schemes for older people, learning disabled people and those experiencing mental distress, the Expert Advisory Panel were surprised at the lack of scale of specialist housing in Northern Ireland. We took evidence from housing associations who informed us they were ready and willing to develop more specialist housing for a variety of different needs. However, we gained the impression that **housing tended to be viewed as a peripheral activity in relation to adult care and support**. Except for a few innovative examples of provision it was somewhat under the radar of the adult care and support system.

Evidence from our visits and from our experience of specialist housing would demonstrate that housing can be an essential part of a response to supporting disabled people and older people, in their own homes and remaining close to their own communities. Extra care, retirement villages, and forms of supported housing combine the benefits of maintaining your 'own front door' with preventative intervention and improved outcomes for people.⁵²

50. <https://www.england.nhs.uk/ourwork/new-care-models/vanguards/care-models/care-homes-sites/airedale/>

51. RCSLT response to Call for Evidence

52. Collaborative Research between Aston Research Centre for Health Ageing and the ExtraCare Charitable Trust (2015) Aston University

Of course everyone will make different choices and many people will choose to remain in their own home for as long as possible, but evidence from the rest of the UK and around the world points to well-designed specialist housing as being a positive choice for many and that it has demonstrably positive role to helping people maintain their independence and wellbeing.⁵³

The Cedar Foundation, for example, supports over 55 individuals with physical disabilities, acquired brain injury and learning disabilities in four supported living projects using SMART technology across Belfast and Lisburn. Individuals live in single or twin occupancy apartments which are enabled with a range of assistive technology to support independent environmental control such as access to property, opening windows, closing blinds and managing heating. These services have been independently evaluated and demonstrated to have a significant positive impact on the functional independence of the tenants living there. In one evaluation⁵⁴, researchers found that tenants particularly valued that they were able to have their own personal space (many had previously lived in residential care) and that the

housing model had given them much greater choice and control over their lives, which in turn had enhanced their personal confidence. This growth in confidence was also reported to have had a positive effect on other areas of their lives, including social and community inclusion and feelings of personal contentment.

Specialist housing can also be engaged as a hub within communities to provide access to social events, information and advice, thus providing an 'asset' for a connected community. Specialist housing is of course only one aspect of housing provision. It has long been the case that in the absence



Shared Lives is a service that provides family-based support for older people and people with disabilities. It enables people to experience ordinary family and community life and receive personal care outside more traditional care settings.

Central to the ethos of Shared Lives is the matching process which offers service users the opportunity to be matched to a Shared Lives carer in the community based on their interests and preferences. This offers a level of personalisation and choice not often available with other services.

There are four Shared Lives schemes in Northern Ireland, which are regulated by RQIA with annual inspections. The schemes support over 300 service users thanks to nearly 190 Shared Lives carers. Evidence suggests Shared Lives costs less than other forms of care: on average £26,000 a year less for people with learning disabilities, according to a detailed independent cost comparison carried out in three areas by Social Finance. These are tangible savings and do not include savings associated with better outcomes and the associated evidence of less use of health and crisis services.

Source: (<http://www.communitycatalysts.co.uk/social-finance-investing-in-shared-lives-july-2013/>)

of suitable accommodation, people often cannot be supported in their own homes. It is clear that better housing which was 'life-long' fully accessible would enable people to live independently and thus remain in their own communities, with or without formal care or family support. Strategies to develop standards for lifetime housing as well as lifetime neighbourhoods are now well established⁵⁵ if not yet implemented. Unfortunately, new developments in specialist housing seem to have considerably slowed in Northern Ireland. The reasons for this are twofold. There appears to be a lack of a positive recognition of the contribution of housing as part of aligned social care strategy and there is a lack of funding. **We believe that the role of housing as an integral part of an aligned care and support system is a core area which requires significantly greater attention and encouragement.**

Of course housing based options are not only achieved through new bricks and mortar. Shared Lives⁵⁶, for example, connects young and older people with support needs to families and carers providing a community based option.

53. Housing, prevention and early intervention at work: a summary of the evidence base (2011) Housing LIN Viewpoint

54. Evaluation of Impact of Assistive Technology at Ardkeen and Hillmount Court, Supported Living Options, Belfast, Social Research Centre/Ulster University 2008

55. Department for Communities and Local Government (2008) Delivering Lifetime Homes, Lifetime Communities – a national strategy for housing in an ageing society; Lifetime Neighbourhoods (2011) for a summary of literature and case examples

56. Information on Shared Lives <http://sharedlivesw.org.uk/what-is-shared-lives/>

Towards a collaborative accountable care system

In the Bengoa report much was said about creating an 'accountable care system' (p4). We believe that the same principles outlined in 'Systems, Not Structures' should extend to adult care and support. How connected each part is, how well the interfaces work is just as, if not more important, than what each of the parts do. The interfaces need to be softer, more diffuse and more collaborative. All parts of the care and health system need to become accountable, jointly and severally.

“ for the reform within adult care and support to be a success, partnership working... must move from the fringes of the system to become part of the system's core business. [It]... must be encouraged, supported and facilitated, including through the allocation of resources. ”

UNISON

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.

“ Housing providers and Health and Social care have to work hand in hand. ”

INDIVIDUAL

“ We need
culture change
and a change in
public attitudes
–there is a need
for a wider
conversation to
set the context
for change.

WORKSHOP COMMENT

”



TOWARDS A NEW CONCORDAT

Our concluding section turns to the proposed Concordat as the means of stimulating a discussion with the public about the future of adult care and support. This new settlement between the citizen and the state is offered as the most effective way to build public understanding of the purpose of adult social care and recognition of its value. It would also clarify personal responsibility and enable proper consideration of risks. Through greater awareness a shared vision can be agreed and the steps to implementing change can be put in place.

Care and support fit for the 21st Century

Throughout this review the Expert Advisory Panel has sought to make the case for transforming the way that the adult care and support system operates. This is the reason the Proposals Paper was commissioned and in the final section we summarise the key themes we have covered.

In our view the transformation of adult care and support means at the very least:

- Placing the individual citizen at the heart of the system;
- Being clear about the purpose of adult care and support;
- Starting from an asset-based approach with an emphasis on earlier intervention, prevention and planning;
- Strengthening the support available to family carers;
- Rethinking attitudes to risk;
- Refocusing on local communities as networks of resources;
- Valuing the professional



- contribution of the care and support workforce and rewarding them appropriately;
- Ensuring a mixed economy of care and support services includes community-based initiatives alongside formal services which are characterised by relationships of trust and transparency between commissioners and providers;
- Facilitating greater openness to improve diversity and quality of provision;
- Enabling appropriate alignment across adult care and support;
- Revaluing the contribution of adult care and support to society.

However, the very need for a new agreement on what matters to people in relation to adult care and support means that the discussion needs citizens to agree the parameters as well as detail of a reformed system to support people. We are in no doubt that this is a major transformational task which requires many established cultures to change and one which realistically might take 10 years to be fully implemented. **We are mindful also that our remit to develop proposals is considerably easier than the task of turning proposals into actions!**

It had been intended that alongside our review and the development of proposals, separate work would be commissioned to get an expert view on the cost of implementing various proposals. Although we have had the benefit of some systems analysis as a means of exploring the impact of the proposals, no detailed financial modelling has been undertaken.

Notwithstanding the encouraging appetite for change that we have witnessed in our discussions with key stakeholders, we would not wish to underestimate the scale of the reform that is necessary. We have been struck by the high level of interest in the review and the enthusiasm with which people have engaged – and at all levels. The response to the Call for Evidence was positive and in addition we received a significant number of papers, reports and references to follow up. In fact we have continued to receive papers and comments throughout the time we have been meeting. There has been remarkable unanimity in the view expressed that the current system of adult care and support is considered broken and unfit for purpose. **The care and support system is not sustainable ... and everyone with any knowledge of the care and support system seems to know this and acknowledge it.**

A shared vision

It is perhaps not surprising that we met some cynicism that the inadequacies of the system have either been ignored, or periodically tinkered with, to little beneficial effect. In essence there is a growing recognition that the structure of adult care and support does not match the changed demands and expectations of the 21st century. This is hardly surprising given that the origins of the Welfare State are now 70 years old. However, most of the views we have heard are those of the 'professionals' with a knowledge of the adult care and support system. Arguably there is much less understanding amongst most members of the public. Typically, people experience the care and support sector at times of personal crisis when they find the system confusing and difficult to navigate. There is insufficient information, care services are not part of the health service generally, they are difficult to access and some are means-tested. No wonder many people simply don't understand social care.

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. This touches on attitudes to age and disability, risks and responsibilities.

It is therefore much broader than social care or care and support services. We have considered in the report some of the implications where adult care and support borders other services and sectors, such as health and housing, leisure and employment. 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.** It would be a new settlement between the individual and the State.

The development of a Concordat is fundamental to transforming the experience of care and support to ensure it is truly person-centred and able to challenge the notion of a risk-averse culture which appears to have developed around services. Our proposal for a new settlement between individuals and the State is only the starting point to raising awareness about the purpose of adult care and support and its relationship to aspects of public health, enabling people to maintain their independence and plan for future needs. It is evident that in Northern Ireland (as elsewhere in the UK and beyond) public understanding of care and support systems is severely limited, with public perceptions of the adult care sector often incorrectly assuming it is already a part of the NHS. Although there are pockets of truly integrated provision it is far from the norm. It seems reasonable therefore to suggest that this lack of understanding contributes to a lack of appreciation of the complexity of the current system and in turn a devaluing of its place and purpose.

Developing a new Concordat would provide the opportunity to engage the wider public in a conversation about what adult care and support should be for, how it should be organised and managed, who might deliver services and how they should be costed and funded. This would bring a measure of transparency to the processes that surround adult care and support including procurement and regulation. It would enable people to better understand how care and support services link to health, housing, transport, leisure and other services. The anomalies that exist in the different ways in which adult care and support services are funded compared to the healthcare sector could also be clarified. Accountability, attitudes to risk, choice and control, rights and entitlements could be properly considered alongside responsibilities. The process could include setting parameters for profit by those providing care services and agreeing that the professional task of caring deserves to be rewarded with at least the Living Wage. The infrastructure to facilitate scalability of local initiatives would be necessary alongside new ways of working for existing care and support services. Ideally such community development would also involve multidisciplinary working with professionals from primary health.

“ A facilitated debate should take place to consider the balance of responsibility between the state and the individual. ”

Despite the fact that very many people's lives are directly touched by the provision of adult care and support services the understanding of social care remains patchy at best. As life expectancy rises, and medical advancements develop, we can assume that many more people will live longer with an increased likelihood of the need for some support at a later stage in life. A better understanding of the service offer and what it seeks to do has to be a good thing. Similarly improving the public awareness of services including availability, quality, regulation, charges and the ways in which services are managed would help to reinforce their contribution to society as a whole. **It is vital that the public understand the difficult choices now implicit in a system widely considered to be broken and unsustainable.**

Principles underpinning the Concordat

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. In our view the discussion necessary to refine the Concordat would best be undertaken through a process of genuine involvement in which the elements relating to adult care and support are co-produced by those regarded as 'experts by experience'. Furthermore, it is our view that it is necessary to ensure that the Concordat is informed by the following fundamental principles:

- A human-rights approach;
- Person-centred and self-directed;
- Simple and easy to understand;
- Transparent;
- Fair and equitable;
- Flexible and responsive;
- Clarifying rights and entitlements alongside responsibilities;
- Suitably aligned with healthcare, the NHS and other key partners;
- Affordability and value for money.

However, we want to make explicit our view that the very process of developing and designing the Concordat would, in itself, need to determine the appropriate underpinning principles.

Once agreed the widest promotion of the Concordat will be necessary and, we would suggest, should form a part of the curriculum in schools so that children and young people have the opportunity to discuss the issues of future care and support and have the opportunity to understand the implications from an early age.

The challenges that this review was established to consider are substantial.

And they are being faced by all the countries of the UK and far beyond. The Expert Advisory Panel had a brief to provide proposals on the nature of the reform needed to ensure that the future system of adult care and support in Northern Ireland is "both sustainable and

designed to respond to individual preferences about how needs are met.” The evidence we have received and the discussions that have followed reinforce the view that the social care system is probably one of the least understood parts of our welfare system.

'Rebooting' the care and support system

During the discussions we have had with people with different interests in the system it has become ever more apparent that meeting the challenges of individual preferences within a sustainable system of care and support will only be possible with major reform. We have argued strongly that doing a bit here and a bit there just won't do it. Isn't this really what has been done many times before? Incremental adjustments might have worked in the past to hold structures together so that services could continue to operate, but so many things have now changed and new demands and expectations mean that there will be further pressures on the fragile system of care and support.

In producing this Proposals Paper and reflecting on the issues that have been raised with us we have sought to direct our attention at areas we feel have the potential to make a difference to reforming the system of adult care and support. We therefore offer a limited number of proposals as they are the really core elements that need to change. The proposals within this report, and the proposed Concordat that we argue flows from our findings, are intended to be implemented as a package of measures to stimulate and embed the necessary change to reform and 'reboot' the system. Whilst it would obviously be possible to pick out proposals from this report as individual recommendations we do not intend them to stand alone. We want to emphasise this point as strongly as we can. **Only through a co-ordinated approach of taking forward the proposals will a successful implementation be possible and real change achieved.**

Our final proposal is:

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.

LIST OF PROPOSALS

Proposal 1

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 HSC Trusts, together with other key bodies in Northern Ireland, take a specific lead in promoting the positive contribution of adult care and support.

Proposal 2

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 that mechanisms to stimulate such models are facilitated as a matter of priority.

Proposal 3

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.

Proposal 4

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 5

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.

Proposal 6

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 7

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.

Proposal 8

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 9

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 support models.

Proposal 10

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 11

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 12

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.

Proposal 13

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 14

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 15

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.

Proposal 16

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.

EXPERT ADVISORY PANEL ON ADULT CARE AND SUPPORT SUPPORTING ANNEX

Background to Establishment of Panel

This paper 'Power to People: Proposals to Reboot Adult Care and Support in Northern Ireland' is the second stage in a three stage process the Department of Health is undertaking to reform adult care and support services. This process began in September 2012 with stage one, an extensive consultation on the discussion document 'Who Cares? The Future of Adult Care and Support in Northern Ireland'. This document sought to build public consensus on the need to reform care and support, given the challenges the system was facing and will continue to face in the years to come. That consultation ran until March 2013, receiving over 180 responses and reaching over 600 people through public meetings and focus group sessions. A paper summarising the findings of the Who Cares? consultation can be accessed at the following link: <https://www.health-ni.gov.uk/publications/who-cares-consultation-analysis-report>.

The second stage of the Reform process was initiated with the establishment of a Project Board and Project Team, which began the process of developing a stage two paper for public consultation that would outline draft proposals for change. Then, in early 2016 the then Minister for Health, Simon Hamilton, announced his intention to appoint an independent panel of experts to consider and review adult care and support.

On 5 December 2016 the former Health Minister, Michelle O'Neill, announced the establishment of the Expert Advisory Panel on Adult Care and Support. Des Kelly OBE and John Kennedy were appointed to the Panel as independent experts with a wealth of experience in adult care and support policy development and delivery. The Panel was tasked with producing robust, evidence-based proposals for change. This was one of the key commitments outlined in 'Health and Wellbeing 2026: Delivering Together', a 10 year vision for health and social care.

The Expert Advisory Panel on Adult Care and Support commenced their work on 5 December 2016. The Panel's Terms of Reference can be found at Appendix A to this paper.

Call for Evidence

To assist the Expert Advisory Panel in undertaking their work, a Call for Evidence was also launched on 5 December 2016, seeking evidence from stakeholders in relation to the challenges facing adult care and support, existing examples of good practice and potential solutions or reforms. The Call for Evidence sought evidence under six Priority Areas:

1. Empowering people to make positive choices and plan for the future
2. Supporting people to regain, retain and maintain their independence
3. Supporting carers
4. Choice and control
5. An effective, innovative and resilient care and support market underpinned by a valued social care workforce
6. Financial sustainability

In total, 46 separate submissions were received from a range of organisations and some individuals. An additional 46 papers were also submitted as supplementary evidence. A list of respondents is provided at Appendix B. We have chosen not to publish the names of those individuals who have responded in a private rather than professional capacity. A number of respondents requested that their responses not be published or quoted; this has been respected and no references to those responses have been included in the Expert Advisory Panel's report.

Each of the responses were individually read and analysed by the Expert Advisory Panel and the Department of Health, and the key points under each of the Priority Areas were collated in a spreadsheet to support the Panel in drafting their report. The table below provides a short synopsis of some of the views, suggestions and examples shared in submissions to the Call for Evidence. This does not reflect every response submitted, but rather gives a flavour of some of the points made.

Priority area	Responses
<p>1: Empowering people to make positive choices and plan for the future</p> <ul style="list-style-type: none"> • Initiatives which encourage positive lifestyle choices; • Most effective means of providing information. 	<p>Good evidence of local projects:</p> <ul style="list-style-type: none"> • Southern Trust (walking, Cycling for Health, Cook it), MEEAP Ageing Well and Reaching Out Programme (156 Age Champion Volunteers), Western Trust Later Years sub-group Health and Wellbeing Plan, YMCA Lisburn project supporting and educating young adults with a learning disability to choose a healthy lifestyle; <p>Potential of Active Ageing strategy to deliver in this area;</p> <p>UU have developed a training programme and manual to assist professionals to work with families to make a future plan;</p> <p>Information shouldn't be digital by default. One stop shop supplemented by advocacy services. Mencap give example of wraparound one stop shop for children's services and disabledgo.com website;</p> <p>Consider NHS Accessible Information Standard;</p> <p>Needs to be a review of legislation as a first step.</p>
<p>2: Supporting people to regain, retain and maintain independence</p> <ul style="list-style-type: none"> • Local initiatives; • Improving awareness of community support; • How services can be redesigned to promote independence; • Working more closely with housing, transport and technology. 	<p>Good evidence of local projects:</p> <ul style="list-style-type: none"> • Coalition of Community Groups (Good Neighbour, Home Secured, Schools Volunteering, Good Carer projects), Mencap (Link Me, Lifestyle Support, Golden Lane Housing), Western Trust flexicare, Beyond Words Peer Support, CLARE project – positive outcomes i.e. social connectivity, clients treated with dignity and respect; <p>Local groups an effective means of sharing information, e.g. Age NI's Age Sector Networks. Also suggestion of preventative visit (COPNI);</p> <p>Support for role of a Navigator (e.g. dementia), possibly linked to older person's support hub;</p>

Priority area	Responses
	<p>Should be a regional database of events/activities. Western Trust has a local one and Belfast Trust is developing a community hub;</p> <p>Number of suggestions about how we could better promote independence:</p> <ul style="list-style-type: none"> • Expansion of Shared Lives around hospital interface, development of Circles of Support to act as a community around service users, Living Well model (Cornwall evidence suggests increased wellbeing and reduced acute and social care costs); • Move towards outcome-based commissioning; • Care homes could become community hubs for local hospitals; • Implement service models such as Living Well. <p>Technology: Risk-averse nature of HSC. Easy access video technology can help with social isolation, apps can prompt medicating, eating and drinking. Remote monitoring of vital signs or falls. SOL Glasgow given as an example of low level technology which has enabled service users who required 1:1 supervision to cope on their own for some time. Also Good Morning NI Connected Health Tech pilot showed improved wellbeing and intergenerational connection and there are plans to extend this to the wider population.</p> <p>Housing: Different budget cycles make alignment difficult. Federation of Housing Associations suggests that there is huge potential for assistive technology but this is restricted by lack of clarity on funding responsibilities. Supporting People – voids/ responsibility between partners.</p> <p>Transport: Ensure Regional Transport strategy is taken forward. Example schemes such as Rural Lift, volunteer/buddy lift.</p>

Priority area	Responses
<p>3: Supporting Carers</p> <ul style="list-style-type: none"> • Effective support for carers; • Initiatives which can encourage people to become/remain carers. 	<p>Good examples of effective services:</p> <ul style="list-style-type: none"> • Shared Lives (evaluated by Cabinet Office) and Mencap's Caring Breaks (95% of carers felt the service had reduced their stress levels). <p>Key features include early identification, wider public recognition of carers, more training.</p> <p>Consider approach in Netherlands – preventative counselling and support offered. Assessment must be carer-blind. Carer's Assessments – lack of statutory basis an issue and there needs to be resources available to respond to those assessments.</p> <p>Information important - Consider role for Carer Navigators. Also Shared Care Scotland's one stop shop.</p> <p>Impact on employment a big factor. Consider Scotland's 'Carer-Friendly' accredited Employer scheme.</p>
<p>4: Choice and Control</p> <ul style="list-style-type: none"> • Barriers; • Initiatives which empower; • Balance between risk and choice. 	<p>Barriers include lack of professional knowledge of range of options, the availability of services to buy and the low rate of SDS – not high enough to attract skilled personal assistants. Also fear of unknown, rules on top-ups restrict choice, inflexibility of commissioning.</p> <p>Empowering – increasing staff awareness, consider Individual Service Funds as a means of administering Direct Payments, use social and community networking. Positive Futures is the NI-rep on the UK-wide National Brokerage Network.</p> <p>Majority view that right to make a choice should come first but concern among some that choices have to be informed and decisions safe (which unregulated SDS may not be). Consider DH document 'Nothing ventured nothing gained' re. risk enablement.</p>

Priority area	Responses
<p>5: Care and Support Market/ Workforce</p> <ul style="list-style-type: none"> • Challenges specific to NI; • How do we improve the market; • How do we improve the experience of the workforce. 	<p>Impact of regional rate and regional contract needs to be considered: regional rate assumes everyone has the same level of need, no promotion of improving outcomes, smothers creativity.</p> <p>Other challenges include staff turnover, low domiciliary care rates, current model of procurement discouraging the sharing of ideas and expertise.</p> <p>NI market isn't resilient as evidenced by home closures. Capital investment has slowed because banks are reluctant to lend.</p> <p>Workforce a challenge – IPPR dashboard suggests up to 10% vacancies in the workforce.</p> <p>Need for review of:</p> <ul style="list-style-type: none"> • needs assessment; • rates paid for care (including VfM audit comparison of statutory and independent sectors). Suggestion of a price regulator; • skill mix required (Standard 41 highlighted as a major concern. Four Seasons have developed the CHESS model of staffing) <p>Should consider market oversight measures as per England.</p> <p>Quality – Four Seasons introduced a Quality of Life Programme to improve quality; Southern Trust established an Independent Sector Governance Committee.</p> <p>Workforce summary – career progression, terms and conditions, training and development. Also social care pays apprenticeship levy but doesn't benefit from it – should be explored. Consider economic value of the workforce. Focus on people's core values to attract the right workforce. Consider 'I Care' ambassadors developed by Skills for Care in England. Ensure workforce has adequate time to carry out tasks and enable meaningful engagement.</p>

Priority area	Responses
	<p>Consider new carer roles to enable career development. Four Seasons suggests an advanced healthcare assistant role would help.</p>
<p>6: Financial Sustainability</p> <ul style="list-style-type: none"> • Evidence of efficiencies; • Unique NI factors that should be taken into account re. charging; • Evidence of impact of charging; • Measures to address perceived unfairness of charging for residential care 	<p>Alternative ways of supporting people - Shared Lives suggests it costs less than other forms of care for both people with a learning disability and mental health needs. Social Farming suggests for every £1 invested, £3.50 is returned in benefits.</p> <p>UNISON suggests removing the purchaser provider split would release funding.</p> <p>Role of care homes in facilitating timely discharge should be more fully explored. Thinktanks like Republica have suggested the creation of a Fast Track Discharge Fund with funds redirected from hospitals to residential care.</p> <p>Residential care supported by in-reach nursing could support some clients currently in more expensive nursing homes.</p> <p>Charging – some support for considering all benefits in charging but taking into account factors such as levels of pensioner poverty. Suggested that any charging would have to be coupled with investment.</p> <p>No measures suggested to address the issue of unfairness.</p>

STAKEHOLDER ENGAGEMENT

Meetings and Visits

The Expert Advisory Panel's contract was for 30 days over five months (December 2016 to May 2017). During this time they spent 18 days in Northern Ireland and 12 days working from their home base in England.

On the days the Panel spent in Northern Ireland, they met with a wide range of key stakeholders and visited a number of services. During these visits the Panel were also able to meet and speak with people using services, carers, and professionals in the care and support system.

It was not possible for the Panel to meet face-to-face with Professor Bengoa, but they were able to consult with him via teleconference sharing a late draft of the report. The Panel were greatly encouraged by the feedback and his observations on linkages and coherence in relation to his work on the healthcare system.

Information on all meetings and visits is provided in Appendix C.

Adult Care and Support Reference Group

Throughout the course of their work, the Panel, have sought to engage meaningfully with the wide range of interested parties and stakeholders. To promote and facilitate service users' and carers' involvement, the Patient Client Council established an Adult Care and Support Reference Group on behalf of the Department of Health. This was intended to provide an independent mechanism to facilitate service users' and carers' engagement with the Panel and the Reform process. The Panel met with the Reference Group on two occasions: in early February 2017 to present their early views following the close of the Call for Evidence, and again in late April 2017 to present a summary of their draft report. The Reference Group also provided written evidence to the Panel to assist in their work. A short summary of some of the comments and suggestions made by the Reference Group is outlined below.

- government departments need to work significantly closer together to respond to the needs of the population;
- need to see a greater acknowledgement of the needs of other populations, specifically younger people with disabilities;
- need a genuine commitment and dialogue regarding preventative care;
- need a 'mutual approach' to service delivery based on 3 elements: prevention, performance improvement and partnership working;
- service users and carers should be empowered to determine the level of risk acceptable in their own homes and communities, e.g. the current menu of services is restricted by standards and regulations;
- recommended maximising the use of volunteering and training people in

- other walks of life who would like to take on community volunteering;
- need to look at the whole community as a workforce in terms of training and service development;
- family carers are part of the workforce and there is a need to define 'mandatory' training for carers;
- it should not always be seen as the responsibility of parents to continue caring into adulthood;
- carers should be protected and supported in their role;
- there is a legal right to choose not to be a carer;
- families need to be supported in planning for the future;
- it is important to have an open discussion about funding;
- concern about the role of for-profit providers;
- need to start other conversations on topics such as; reinstating prescription charges, increasing National Insurance, charging for domiciliary care; and younger people taking out insurance policies to cover future care costs;
- concern that funding is weighted towards acute services - this must be addressed for care in the community to have a solid foundation.

In addition to the Group's discussion, a number of members also shared papers and submissions with the Panel. The Panel were very grateful for the opportunity to meet with and work with Reference Group members, whose input throughout the process played a crucial role in shaping their thinking and the Proposals Paper.

Workshops

In early March the Department of Health facilitated three workshops to support the Panel in testing their early ideas with a range of stakeholders. These workshops took place in Craigavon, Derry and Belfast, and each workshop covered a different theme:

Date	Venue	Theme
Monday 6 March 2017	Oxford Island, Craigavon	Choice, Control and Community Engagement
Tuesday 7 March 2017	City Hotel, Derry	Building Capacity and Sustainability
Wednesday 8 March 2017	Malone House, Belfast	Workforce

In total, around 130 people attended the workshops, although this may include an element of double counting as some people attended more than one event. The Panel were very impressed at the high levels of engagement during each of the workshops, and found the feedback received to be of great benefit in further shaping and consolidating their thoughts.

Some of the issues raised are noted below:

- Support greater emphasis on prevention – including role of voluntary and community sector, addressing social isolation, promoting active ageing, housing solutions and supporting carers;
- Funding needed to pump prime new services and build public support;
- Small amount of targeted community support can make an enormous difference;
- Developing the workforce will help reduce risk;
- Service user should control the money – in vast majority of cases it will be used appropriately and with positive outcomes;
- Different budgets within Trusts can act as a constraint;
- Need sufficient and appropriate housing stock to allow more people to remain at home;
- Can't allow technology to become an excuse to isolate people from human contact;
- Need to consider that younger people with disabilities do not have the means to build up capital to pay for social care;
- Challenge of balancing choice (greater choice equals greater complexity) and simplicity;
- Perhaps too much emphasis on older people – consider younger people with progressive conditions;
- Build on potential of community planning through local government;
- Need to consider the impact on care homes of any introduction of charges for domiciliary care;
- Charging discussion needs to take place in the context of improved/higher quality services;
- Need to avoid race to the bottom;
- Can be difficult to include social value clauses like the Living Wage;
- Commissioning could be done at individual service user level;
- Consider the impact of BREXIT on the workforce;
- Need long term commissioning plan and funding arrangements;
- Need to avoid blame culture, give leaders confidence;
- System should be easier to navigate;
- Needs to be a shift from reactive to preventative;
- Money has to be invested in a planned way to build towards outcomes;
- Service users need to understand at outset what outcomes are sought, and what the agreed journey is;
- Needs to be accredited, transferrable training to enable people to build careers;
- Need to look at bad PR around social care – only the mistakes get reported by media;
- More support needed for carers;
- Concern that the voice of carers is not being heard;
- Pressure on domiciliary care workforce due to increasing complexity of need;
- Standard of service delivery more important than whether a provider is private;
- People need to understand cost of care.

Further details on the workshops, including the questions asked at each event and the organisations who attended, can be found in Appendix D.

APPENDIX A

EXPERT ADVISORY PANEL ON ADULT CARE AND SUPPORT

Terms of Reference

The Expert Advisory Panel will supplement the work of the Core Team in developing proposals for change in the following areas:

- Steps which can be taken to empower people to encourage positive lifestyle choices and planning for the future;
- Supporting people to regain, retain and maintain their independence through, for example, a focus on preventative services and technology;
- Supporting carers in their caring role;
- Facilitating choice and control over how care and support needs are met;
- Ensuring an effective, innovative and resilient care and support market underpinned by a respected, quality social care workforce; and
- Measures which can be taken to ensure the financial sustainability of the care and support system.

In this context, the Panel will help shape proposals through:

- A call for evidence inviting stakeholders to share ideas on potential reforms;
- A review of evidence and international best practice in these areas;
- The identification of further areas for potential reform which could contribute to a better system of support; and
- Assessing impact of reforms on balance of responsibility between government, people who use services and carers.

The Panel will report directly to the Minister.

APPENDIX B

List of Respondents to Call for Evidence

Reference Number:	Organisation:
CFE1	Chartered Society of Physiotherapy
CFE2	Individual
CFE3	Royal College of Speech & Language Therapists
CFE4	Prof Assumpta Ryan, Professor of Ageing and Health, Ulster University
CFE5	Acquired Brain Injury Rehabilitation Team, Southern Health and Social Care Trust
CFE6	Bardan Cottage
CFE7	Carers NI
CFE8	Mid & East Antrim Agewell Partnership (MEAAP)
CFE9	CLARE CIC
CFE10	Optimum Care & Domestic Care Group
CFE11	UK Home Care Association (UKHCA)
CFE12	Dalriada Pathfinder Partnership
CFE13	Independent Health and Care Providers (IHCP)
CFE14	Positive Futures (1)
CFE15	MS Society
CFE16	MD Healthcare
CFE17	Southern Health and Social Care Trust
CFE18	Confederation of Community Groups (CCG)
CFE19	Shared Lives Plus
CFE20	Social Farming
CFE21	Dr Laurence Taggart, Lead for the Centre of Intellectual and Developmental Disabilities, Ulster University
CFE22	Four Seasons Health Care
CFE23	Western Health and Social Care Trust

Reference Number:	Organisation:
CFE24	RDB Star Rating
CFE25	Praxis Care
CFE26	Positive Futures (2)
CFE27	Commissioner for Older People in Northern Ireland (COPNI)
CFE28	Northern Ireland Social Care Council (NISCC)
CFE29	Association for Real Change (ARC)
CFE30	The Cedar Foundation
CFE31	Cruse Bereavement Care NI
CFE32	Individual
CFE33	Age NI
CFE34	Dr Lorna Montgomery, Lecturer in Social Work & Dr Bernie Kelly, Senior Lecturer in Social Work, Queen's University Belfast
CFE35	RQIA
CFE36	UNISON
CFE37	Mencap NI
CFE38	Lancashire Care Association Co. Ltd
CFE39	Carer Coalition, incl. Age NI, Cause, MacMillan Cancer Support, MS Society, Positive Futures, Carers NI, Mencap NI, Detail Data, and Northern Ireland Council for Voluntary Action (NICVA)
CFE40	Northern Ireland Association of Social Workers (NIASW)
CFE41	College of Occupational Therapists
CFE42	Individual
CFE43	Northern Ireland Practice and Education Council for Nursing and Midwifery (NIPEC)
CFE44	Individual - Easy Read
CFE45	Positive Futures (Easy Read response)
CFE46	Health and Social Care Board (HSCB)

APPENDIX C

Meetings and Visits

Date	Meeting/Visit
5 December 2016	<p>Meeting with Reform Team:</p> <p>Chris Matthews, Director of Mental Health, Disability and Older People's Policy, Department of Health (DoH), and Reform Project Manager Dean Looney, Reform Core Team, DoH Taryn McKeen, Reform Core Team, DoH Ruth Todd, Reform Core Team, DoH</p>
	<p>Meeting with DoH Adult Social Care Policy Leads:</p> <p>Jerome Dawson, Head of Elderly and Community Care Unit Colin Dunlop, Acting Head of Physical and Sensory Disability Unit Alison McCaffrey, Head of Learning Disability Unit Andrew Dawson, Head of Mental Health Policy and Legislation Unit</p>
	<p>Meeting with Reform Project Senior Responsible Owner:</p> <p>Seán Holland, Deputy Secretary and Chief Social Work Officer, DOH</p>

Date	Meeting/Visit
9 January 2017	<p>Meeting with DoH Social Work professionals:</p> <p>Jackie McIlroy, Acting Deputy Chief Social Work Officer Jillian Martin, Lead Social Work Professional for Older People and Community Care Christine Smyth, Strategy Director (Social Work)</p>
	<p>Meeting with:</p> <p>Kathy Fodey, Director of Regulation and Nursing, Regulation and Quality Improvement Authority (RQIA)</p>
	<p>Meeting with representatives of provider organisations:</p> <p>Colin Angel, Policy and Campaigns Director, UK Home Care Association (UKHCA) Pauline Shepherd, Chief Executive, Independent Health and Care Providers (ihcp) Carol Cousins, Managing Director, Four Seasons Northern Ireland</p>
	<p>Meeting with Department for Communities (DfC):</p> <p>Stephen Martin, Housing Lead Ronan McClean, Housing Affordability Branch</p>

Date	Meeting/Visit
10 January 2017	<p>Meeting with AgeNI representatives:</p> <p>Linda Robinson, Chief Executive Duane Farrell, Charity Director Paschal McKeown, Head of Policy and Influencing</p>
	<p>Visit to Hemsworth Court (supported living facility for people with dementia).</p> <p>Meeting with Belfast Health and Social Care Trust representatives coordinated by Marie Heaney, Co Director, Adult Health and Social Care Services.</p>
	<p>Meeting with:</p> <p>Colum Conway, Chief Executive, NI Social Care Council</p>
	<p>Meeting with Housing Association representatives:</p> <p>Cameron Watt, Chief Executive, NI Federation of Housing Associations (NIFHA) Denise Magill, Director of Support Services, Triangle Housing Fiona McAnespie, Director of Care Services, Fold Housing</p>
	<p>Meeting with UNISON representatives:</p> <p>Patricia McKeown, NI Regional Secretary John Patrick Clayton, Policy Officer Anne Speed, Head of Bargaining and Representation</p>

Date	Meeting/Visit
11 January 2017	<p>Visit to Learning Disability services (supported living facility and Acceptable Enterprises (Larne) Ltd), Northern Health and Social Care Trust, coordinated by:</p> <p>Iolo Eilian, Lead Commissioner for Learning Disability, Health and Social Care Board Alyson Dunn, Assistant Director, Northern Health and Social Care Trust</p>
	<p>Meeting with Office of the Commissioner for Older People in NI (COPNI):</p> <p>Eddie Lynch, Commissioner for Older People in Northern Ireland Evelyn Hoy, Chief Executive Emer Boyle, Head of Legal and Policy Advice</p>
	<p>Meeting with Health and Social Care Board:</p> <p>Kevin Keenan, Assistant Director, Adult Social Care</p>
30 January 2017	<p>Meeting with Reform Team staff to discuss Call for Evidence responses</p>
13 February 2017	<p>Meeting with:</p> <p>Orla Donaghy, Head of Social Care Procurement Unit, Business Services Organisation (BSO)</p>
	<p>Meeting with:</p> <p>Reform of Adult Care and Support Project Board (multi-agency)</p>
	<p>Meeting with:</p> <p>Professor Roger O'Sullivan, interim Chief Executive of the Institute of Public Health (IPH)</p>

Date	Meeting/Visit
14 February 2017	<p>Visit to Meadowvale Court, Cedar Foundation Supported Living unit. Meeting with:</p> <p>Stephen Mathews OBE, Chief Executive, Cedar Foundation Eileen Thomson, Deputy Chief Executive Professor Suzanne Martin, Professor of Occupational Therapy, Ulster University Bria Mongan, Director of Adult Services, South Eastern Health and Social Care Trust Nicola McEvoy, Case Officer, Inclusion Works (Cedar programme) Former Inclusion Works participant Cedar User Forum representative</p>
	<p>Meeting with:</p> <p>Adult Care and Support Reference Group (managed by Patient Client Council)</p>
	<p>Meeting with Carers NI representatives:</p> <p>Clare-Anne Magee, General Manager, Carers NI Simon Hodgson, Director of Scotland and NI Lesley Johnston, Advice and Information Officer</p>
23 February 2017	<p>Meeting with Mencap NI representatives:</p> <p>Margaret Kelly, Director Jamie Greer, Employment & Personal Development Manager Neil Calvin, Area Operations Manager Fiona Cole, Campaigns and Policy Officer Geraldine McGurk, Lifestyle Support Service Manager</p>
	<p>Meeting with Association for Real Change (ARC) representatives:</p> <p>Leslie-Anne Newton, NI Director, ARC Delores Finnerty, Caring Breaks Agnes Lunney, Positive Futures Linda Wray, Presbyterian Board of Social Witness</p>

Date	Meeting/Visit
27 February 2017	Visit to Inspire Wellbeing learning disability service and mental health supported living facility
	Meeting with: Professor Peter McBride , Chief Executive Margaret Cameron , Director of Learning Disability Services Billy Murphy , Director of Mental Health Services
	Meeting with: Sarah Wylie , System Dynamics economist (Department of Finance)
7 March 2017	Meeting with CLARE CIC representatives: Mandy Cowden , Project Coordinator Laura Feeney , Board member
3 April 2017	Meeting with: Jackie Johnston , Deputy Secretary, Delivering Together Transformation Programme
	Meeting with: Richard Pengelly , Permanent Secretary, DoH
12 April 2017	Meeting with Reform Team to discuss draft report.
24 April 2017	Meeting with: Reform of Adult Care and Support Project Board (multi-agency)
25 April 2017	Meeting with: Adult Care and Support Carer Reference Group (managed by Patient Client Council)
	Meeting with: Reform of Adult Care and Support Project Team (multi-agency working group)

Date	Meeting/Visit
18 May 2017	John Kennedy presentation to NICON conference on Panel's work
22 May 2017	Teleconference with: Professor Rafael Bengoa , Chair of Expert Panel who produced "Systems, Not Structures: Changing Health and Social Care"
31 May 2017	Presentation of the final report to the Transformation Implementation Group (TIG) , who are responsible for overseeing the wider transformation programme outlined under "Delivering Together"

APPENDIX D

Workshop Details

Monday 6 March 2017: Choice, Control and Community Engagement	
Venue:	Lough Neagh Discovery Centre, Oxford Island Nature Reserve, Craigavon
Questions:	<ol style="list-style-type: none"> 1. Does there need to be a new concordat? 2. What should the role of carers be and how should they be supported? 3. What does choice and control really mean? 4. What does the perfect system look like for citizens? 5. What is the role of communities and how should they be supported?
Number of attendees:	45
Organisations attending:	Royal College of Speech and Language Therapists (RCSLT), Volunteer Now, Western HSC Trust, Inspire Wellbeing, UNISON, Positive Futures, Four Seasons Health Care, CLARE, Health and Social Care Board (HSCB), Independent Health and Care Providers (ihcp), Business Services Organisation (BSO), NI Local Government Association (NILGA), Cruse, MS Society, Adult Care and Support Reference Group, Southern HSC Trust, Shared Lives, Department of Health (DoH), College of Occupational Therapists (COT), Alzheimer's Society, Centre for Independent Living (CIL), Patient Client Council (PCC), Regulation and Quality Improvement Authority (RQIA), NI Social Care Council (NISCC), Equality Commission NI, NI Association of Social Workers (NIASW), Institute of Public Health (IPH), Northern HSC Trust, Department for Communities (DfC), Rural Support, Domestic Care, South Eastern HSC Trust, Age NI, Department of Finance (DoF).

Tuesday 7 March: Building Capacity and Sustainability	
Venue:	City Hotel Derry, Queens Quay, Londonderry
Questions:	<ol style="list-style-type: none"> 1. What is a fair and clear Charging Policy? 2. Do we need commissioning and who should do it? 3. Is a mixed economy of care the best way of providing care and support? 4. What does the perfect system look like for citizens? 5. How do we better promote innovation and creativity?
Number of attendees:	35
Organisations attending:	NI Federation of Housing Associations (NIFHA), UNISON, Western HSC Trust, Public Health Agency (PHA), Southern HSC Trust, UNISON, NISCC, Law Centre NI, Four Seasons Health Care, Alzheimer's Society, HSCB, Age NI, DoH, PCC, Rural Support, Shared Lives, COT, MS Society, Inspire Wellbeing, Association for Real Change (ARC), Northern HSC Trust, Chartered Society of Physiotherapists (CSP), Domestic Care, Cedar Foundation.

Wednesday 8 March: Workforce	
Venue:	Malone House, Barnett Demesne, Belfast
Questions:	<ol style="list-style-type: none"> 1. How do we empower leaders to deliver change? 2. What does the perfect system look like for citizens? 3. What would an ideal career pathway look like? 4. How can the system be reshaped to place greater emphasis on the value of the workforce? 5. Does it matter if the employer is private, voluntary or statutory?
Number of attendees:	51
Organisations attending:	Southern HSC Trust, South Eastern HSC Trust, Domestic Care, DoH, Adult Care and Support Reference Group, RQIA, Northern HSC Trust, Cedar Foundation, Inspire Wellbeing, NISCC, PHA, RCSLT, Age NI, Four Seasons Health Care, Positive Futures, NIASW, Western HSC Trust, Alzheimer's Society, Shared Lives, Praxis Care, COT, UNISON, CIL, PCC, NI Practice and Education Council for Nursing and Midwifery (NIPEC), HSCB.

NOTES

