# ENABLE Scotland

# Integration of Adult Health and Social Care in Scotland – Consultation on Proposals

# Consultation Response

# September 2012

## Introduction

ENABLE Scotland is the largest voluntary organisation in Scotland of and for children and adults who have learning disabilities and their families. We have a strong voluntary network with around 4000 members in 51 local branches as well as 500 national members throughout Scotland. Around a third of our members have a learning disability. ENABLE Scotland campaigns to improve the lives of people who have learning disabilities and their families and carers.

ENABLE Scotland welcomes the Scottish Government's consultation paper which is clearly linked to a number of longer term policy objectives – such as the commitment to shift the balance of care from institutions to the community, reductions in delayed discharges and improvements in the quality of care.

We recognise the different roles played by health and social care services in the lives of people who have learning disabilities. Health services exist to prevent people from illness as well as diagnosing and treating illnesses, where as social care services exist to provide support which increases an individual's independence. Integrating health and social care services must be the means to achieving an end – in short, ensuring that outcomes for people who use health and social care are improved – rather than being the end itself.

It may be helpful if the Scottish Government outlined a clear set of principles on the face of the new Health and Social Care Integration Bill to set out the guiding values behind the integration of health and social care.

ENABLE Scotland is, in principle, in favour of greater integration of health and social care and the principles behind these proposals. We agree that doing nothing is not an option given the financial pressures of providing health and social care services. We believe the proposals are well intentioned in attempting to address the gap between health and social care. People who have learning disabilities and their parents and carers want to receive the best service possible from health and social care services – they are less interested in the structure by which it is provided.

During consultation with our members on this issue, however, many people expressed concern about the lack of clear detail within the command paper for groups other than older people. We are particularly concerned that

there is, at present, no mention in the document of how the proposals will affect learning disability services. The Government must clarify how these proposals will affect social care groups beyond older people in the future and produce a clear timescale for change.

We believe that this is of significant importance at a time of reducing public sector budgets and changes to services. Many people who have learning disabilities are being affected by cuts and changes to services and in that climate it is very important to ensure that maximum value is delivered for every pound of public spending. If the conclusion of the Scottish Government is that integration of budgets across health and social care helps to deliver this, we believe that it needs to happen sooner, rather than later.

Our members also expressed frustration at the effect of a lack of joined-up work between health and social care staff. Some people who have learning disabilities said that a lack of joined-up working had caused them to have to stay in hospital for longer whilst arrangements were made for on-going care after they were discharged. In other cases, some people told us that they had been moved into inappropriate short-term settings, including nursing homes, for short periods of time.

As noted in ENABLE Scotland's response to the Scottish Government's 2009 consultation on National Eligibility Criteria for Adult Social Care Services[1], too great an emphasis in social care commissioning is placed upon 'crisis management'. ENABLE Scotland agrees with recommendations within the Commission on the Future of Public Services' 2011 report[2] that prevention requires further priority within commissioning strategies. Failure to give adequate consideration to how people's lives can be enhanced before a crisis will have longer-term social and financial implications.

Some of our members have also expressed the need for greater integration of other public functions – for example health and education – to improve the services they receive. We would like to see the Scottish Government give some consideration to this in the near future.

**Responses to Consultation Questions**

**Question 1: Is the proposal to focus initially, after legislation is enacted, on improving outcomes for older people, and then to extend our focus to improving integration of all areas of adult health and social care, practical and helpful?**

We understand the rationale for beginning the process of change specifically for older people's services, as some of our members have expressed, "you have to start somewhere". A number of the initial drivers for integration, however, appear to relate to matters such as delayed discharge and shifting

[1] http://www.enable.org.uk/enabledirect/publications/Documents/CP%20-%20National%20eligibility%20criteria%20for%20adult%20social%20care%20and%20waiting%20times%20for%20personal%20and%20nursing%20care.pdf

[2] http://www.scotland.gov.uk/Publications/2011/06/27154527/0

the balance of care for older people. These matters are not as relevant to people who have learning disabilities and we are concerned that any delay to full integration may lead to the creation of two distinct systems, one integrated and one not, albeit it temporarily.

The consultation document acknowledges the importance of integrated health and social care for groups beyond older people, but at present there is no mention in the document of how the proposals will have an impact for learning disability services. We believe this should be clearer. It would also be helpful if the Scottish Government could outline a timescale by which full integration for all areas of adult health and social care will be achieved.

We believe that this is of significant importance at a time of reducing public sector budgets and changes to services. Many people who have learning disabilities are being affected by cuts and changes to services and in that climate it is very important to ensure that maximum value is delivered for every pound of public spending. If the conclusion of the Scottish Government is that integration of budgets across health and social care helps to deliver this, we believe that it needs to happen sooner, rather than later.

> It is vital that plans are not developed for older people and then simply applied to younger adults whose needs are often very different. The type of life an older person wants to live is quite different to that of someone who has a learning disability. Keeping someone safe might be a key priority of care for an older person, but getting out and about and staying independent is often the top priority for a younger person who has a learning disability. The system must be flexible enough to enable people with learning disabilities to lead independent lives.

At present there is no compulsion to transfer children and young people's services, and we have concerns that this may affect the transition from children to adult services – already a very stressful time for many families.

**Question 2: Is our proposed framework for integration comprehensive? Is there anything missing that you would want to see added to it, or anything you would suggest should be removed?**

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this, we believe that it needs to happen sooner, rather than later.

As noted within a recently published shared statement from third sector organisations[3], integration of health and social care throws up significant problems in relation to the universality of health services which are free at the point of delivery and social care services which are variable across the country and subject to charges and eligibility criteria. Further clarity is required on the future role of community care charges across Scotland.

We are also concerned about the existing cultural differences between the attitudes of health and social care staff to disability. The medical model of disability – that disabled people are defined by their condition and that they are to be cured or cared for – is still prevalent in the health field rather than the social model of disability – that disability is caused by the society in which disabled people live.

If a predominantly risk-averse culture exists across healthcare staff, we are concerned that after integration this could work against the development of self-directed support (SDS) across Scotland. It is a central tenet to the SDS agenda that people are given the opportunity to take risks and control and use money in the way they choose. Under an integrated system there is the potential for some conflict with the personalisation agenda which could challenge the local implementation of self-directed support. A clearer fit with the self-directed support agenda is required to ensure that integration and self-directed support are progressed together.

An important outcome of the integration of health and social care should be to ensure that a much more common view of disability is fostered by both health and social care professionals. Third sector and provider organisations have a vital role to play in making this happen. Anecdotal evidence from one Community Health Partnership which has moved towards a more integrated approach suggests that where staff from both sectors work closely together, health staff move increasingly towards the social model of disability. We believe that bringing about such an outcome could lead to a more balanced and holistic view of disability across health and social care services.

**Question 3: This proposal will establish in law a requirement for statutory partners – Health Boards and Local Authorities – to deliver, and to be held jointly and equally accountable for, nationally agreed outcomes for adult health and social care and for support to carers. This is a significant departure from the current, separate performance management mechanisms that apply to Health Boards and Local Authorities. Does this approach provide a sufficiently strong mechanism to achieve the extent of change that is required?**

It is of upmost importance that the delivery of social care services is driven by outcomes. People who have learning disabilities and their parents and carers want to receive the best service possible from health and social care services – they are less interested in the structure by which it is provided. However,

[3] http://www.ltcas.org.uk/download/library/lib_5012702b2cf56/

we believe that a set of jointly agreed outcomes for which partnerships will be accountable within both NHS and local authority structures is a positive step forward.

As mentioned previously, the consultation document acknowledges the importance of integrated health and social care for groups beyond older people, but at present there is no mention in the document of how the proposals will have an impact for learning disability services. We believe this should be clearer. It would also be helpful if the Scottish Government could outline a timescale by which full integration for all areas of adult health and social care will be achieved.

Reporting and scrutiny should be robustly applied, and there should be clear consequences for health and social care partnerships where health and social care outcomes are not being achieved.

**Question 4: Do you agree that nationally agreed outcomes for adult health and social care should be included within all local Single Outcome Agreements?**

It is of upmost importance that the delivery of social care services is driven by outcomes. People who have learning disabilities and their parents and carers want to receive the best service possible from health and social care services – they are less interested in the structure by which it is provided. However, we believe that a set of jointly agreed outcomes for which partnerships will be accountable within both NHS and local authority structures is a positive step forward.

We are concerned that, at present, Single Outcome Agreements are not always sufficiently clear and measurable, and not enough independent scrutiny is brought to bear in assessing progress towards them. This must be addressed.

We are delighted to see that the proposed Health and Care Integration Outcomes (Annex A) include the general point that unpaid carers are supported and able to maintain their own health and wellbeing. Many of ENABLE Scotland members have cared for people who have learning disabilities for many years.

As acknowledged within the Scottish Government's Carers Strategy, Caring Together[4], for the first time there is a generation of people who have learning disabilities who are outliving their parents. As such, there are more lifelong carers of people who have learning disabilities whose caring responsibility will not cease until their death.

Many older family carers are in their 70s and 80s. These carers are lifelong and having been providing care and support to their sons and daughters from birth. ENABLE Scotland believes that more should be done to support carers

[4] http://www.scotland.gov.uk/Publications/2010/07/23153304/0
[5]

before they reach old age – either to help them continue caring or to stop their day-to-day caring role.

**Question 5: Will joint accountability to Ministers and Local Authority Leaders provide the right balance of local democratic accountability and accountability to central government, for health and social care services?**

The proposals need to more strongly reflect the move towards co-production, and for people to become equal partners alongside service providers. People who use services and unpaid carers can play an important role, alongside professionals, in planning and commissioning. People who use services and carers representatives on HSCP Committees must have the opportunity to influence decision making – including the opportunity to vote on those decisions.

**Question 6: Should there be scope to establish a Health and Social Care Partnership that covers more than one Local Authority?**

During consultation on this issue, some of our members agreed that it would be better if these boundaries were based upon local authority area, rather than wider areas. One group said that local experiences of health staff and social work staff working closely together in one building had been good and this should be adopted across the country.

The current non-coterminous arrangement between health boards, local authorities and Community Health Partnerships may cause some difficulties which are preventing a greater level of joined-up working. For instance, there is a complicated relationship between both North and South Lanarkshire Council and NHS Lanarkshire and NHS Greater Glasgow and Clyde.

We believe that 32 Health and Social Care Partnerships, coterminous with local authorities, would be the most appropriate arrangement. Having the same geographical boundaries will mean that families won't face the problems caused by having social care services provided by one local authority and NHS services located in another.

**Question 7: Are the proposed Committee arrangements appropriate to ensure governance of the Health and Social Care Partnership?**

The proposals need to more strongly reflect the move towards co-production, and for people to become equal partners alongside service providers. People who use services and unpaid carers can play an important role, alongside professionals, in planning and commissioning. A significant bulk of care in the community is provided by unpaid family carers. Many of these carers are getting older and their children are living longer. The Scottish Government should clarify how the role of carers, for instance, can be recognised and valued by all parties "around the table".

People who use services and carers representatives on HSCP Committees must have the opportunity to influence decision making – including the opportunity to vote on decisions. Many of our members have concerns about the level of democratic accountability available in the proposed new structures. Carers and parents must have a significant role on such Committees.

The third sector also has an important role to play in driving such a transformational change. We believe that voluntary organisations should have the opportunity to play a role as an equal, strategic partner.

**Question 8: Are the performance management arrangements described above sufficiently robust to provide public confidence that effective action will be taken if local services are failing to deliver appropriately?**

Since the Community Health Partnership structure was established, our members have noted significant variation in the quality of service being provided. Often this can be put down to the quality of individual members of staff involved in delivering services.

> Reporting and scrutiny should be robustly applied, and there should be consequences for health and social care partnerships where health and social care outcomes are not being achieved. It is also vital that Health and Social Care Partnerships appoint staff with the right skills, values and capacity to deliver quality outcomes for people who use health and social care services.

**Question 9: Should Health Boards and Local Authorities be free to choose whether to include the budgets for other CHP functions – apart from adult health and social care – within the scope of the Health and Social Care Partnership?**

No comments.

**Question 10: Do you think the models described above can successfully deliver our objective to use money to best effect for the patient or service user, whether they need "health" or "social care" support?**

The success or otherwise of the integration of health and social care is dependent on a number of factors – ranging from cultural differences, organisational cultures, priorities, planning and performance management, decision-making, accountability and financial frameworks. ENABLE Scotland does not have a view on which model will be most successful in ensuring that these range of factors are satisfied. Our key concern is that outcomes affecting the lives of people who have learning disabilities are improved.

**Question 11: Do you have experience of the ease or difficulty of making flexible use of resources across the health and social care system that you would like to share?**

No comments.

**Question 12: If Ministers provide direction on the minimum categories of spend that must be included in the integrated budget, will that provide sufficient impetus and sufficient local discretion to achieve the objectives we have set out?**

No comments.

**Question 13: Do you think that the proposals described here for the financial authority of the Jointly Accountable Officer will be sufficient to enable the shift in investment that is required to achieve the shift in the balance of care?**

No comments.

**Question 14: Have we described an appropriate level of seniority for the Jointly Accountable Officer?**

ENABLE Scotland's members have indicated that they welcome the role of a Jointly Accountable Officer in each area. We agree that this must be a senior appointment, with direct authority to make decisions about resource prioritisation. It will be important that this individual is directly accountable to people who use services and their parents and carers.

**Question 15: Should the Scottish Government direct how locality planning is taken forward or leave this to local determination?**

No comments.

**Question 16: It is proposed that a duty should be placed upon Health and Social Care Partnerships to consult local professionals, including GPs, on how best to put in place local arrangements for planning service provision, and then implement, review and maintain such arrangements. Is this duty strong enough?**

No comments.

**Question 17: What practical steps/changes would help to enable clinicians and social care professionals to get involved with and drive planning at local level?**

No comments.

**Question 18: Should locality planning be organised around clusters of GP practices? If not, how do you think this could be better organised?**

No comments.

**Question 19: How much responsibility and decision making should be devolved from Health and Social Care Partnerships to locality planning groups?**

No comments.

**Question 20: Should localities be organised around a given size of local population – e.g., of between 15,000 – 25,000 people, or some other range? If so, what size would you suggest?**

No comments.