

Integration of Adult Health and Social Care in Scotland Proposals

A response from the Neurological Alliance of Scotland

About Neurological Conditions

An estimated one million people in Scotland are living with a neurological condition which has a significant impact upon their lives. Most neurological conditions affect people's quality of life and require ongoing treatment and care.

Neurological conditions are caused by damage to the nervous system, often as a result of illness or injury. Some have a genetic basis and are inherited. Problems of the nervous system usually affect the brain and spinal cord and the nerves and muscles in the body. Neurological conditions can affect all ages and can begin at any time in a person's life.

Background to the Neurological Alliance of Scotland

The Neurological Alliance of Scotland is a forum of not-for-profit organisations and groups representing many thousands of people affected by neurological conditions in Scotland. The Alliance was launched in 2004 to ensure that neurological services are given priority at all levels of health and social care planning. The Alliance enables neurological organisations and groups to campaign together and speak with an influential voice.

The Alliance has three main aims:

1. *Influencing Policy*
To inform and influence policy by bringing the needs of people with neurological conditions to the attention of health and social policy makers and strategists.
2. *Raising Awareness*
To raise awareness and disseminate information about neurological conditions and their impact on individuals and society.
3. *Improvements in care*
To promote improvements in care for people with neurological conditions

The Alliance has the vision that 'People living with neurological conditions will have access to the best care possible, have control over their lives and be able to live free from ignorance and injustice.'

The Neurological Alliance of Scotland welcomes the opportunity to respond to the Integration of Adult Health and Social Care in Scotland Proposals. The consultation questions have been circulated to all 37 member organisations of the Alliance, some of whom intend to submit a direct response. There are some areas of the consultation in which the Alliance does not feel it is qualified to make detailed comment and this is indicated in

the questionnaire.

Consultation Questionnaire

The case for change

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?*

Neurological conditions can affect all ages and can begin at any time in a person's life. Some neurological conditions are life-long and may be present from birth, such as Spina Bifida or cerebral palsy. Other conditions such as Alzheimer's and Parkinson's disease will affect mainly older people. Some neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, occur mainly in adulthood and are progressive meaning that that a person's ability to live independently eventually becomes difficult and they will rely more on appropriate services to assist them.

The Neurological Alliance of Scotland welcomes the Scottish Government's intention to integrate adult health and social care and accepts that it is practical to initially focus upon older people's services. We recognise that this will build upon the work of the Reshaping Care for Older People Change fund though are mindful that the success of this is yet to be assessed. We believe that it will be helpful to ensure that integration of older people's services takes account of the lessons learned through review of the Change fund.

Whilst there is increased prevalence of neurological conditions in older age groups there are many neurological conditions which affect people of working age. Multiple Sclerosis (MS) for example, is a progressive and life long condition, most commonly diagnosed between the ages of 20 and 40 and is the most commonly physically disabling condition affecting young people. The Alliance believes that it is important that the benefits for integration for younger adults with Neurological conditions are worked through as well and would welcome clear timescales and processes for the extension of integration to other groups. It is also essential that integration plans for other groups are appropriate and therefore vital that the plans developed for older people are not viewed as automatically applicable to younger age groups who will often have very different needs and may require different models of service provision.

Whilst the proposals state that the goals of integration are in line with the policy of Self Directed Support (SDS) there is little else concerning SDS. The Alliance believes that the implications of the proposals for SDS and vice versa should be clarified by Scottish Government. SDS has been more extensively rolled out amongst younger age groups and it is important to take this into account.

Outline of proposed reforms

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?

The Neurological Alliance of Scotland believes that in order to deliver coordinated and effective care more than just structural and legislative change is required. Strong leadership, professional and organisational cultural change is also crucial in order to integrate health and social care. The Alliance believes that whilst the framework for integration sets out the aim and objectives for reform it should also make explicit the values and principles that should underpin such legislation. A set of guiding principles based upon equality and human rights should be set out which can bring meaning and relevance to single agency, multi agency and interagency working across adult health and social care services. It may therefore be useful to articulate the underlying values and principles for integration in terms of direction of travel, peoples' assets, human rights, working relationships and role of the third sector. A right-based approach can help to clarify expectations of fair, consistent and respectful experiences and of redress when standards fall below this.

The Alliance would also advise that whilst the goal of achieving integrated, person centred care is welcome, it is important to acknowledge that for many people with neurological illness, some hospital and care home admissions are appropriate and it is crucial that there are no barriers to this. People with complex progressive neurological illness require ongoing access to specialist care from multi disciplinary teams throughout the course of their condition. Whilst remaining at home is desirable there are circumstances in which people with progressive disease, at some point throughout their disease trajectory may find remaining at home is not possible. It will be essential to ensure that budget reallocation within the new integration framework does not result in a reduction in specialist care for those that need it most.

National outcomes for adult health and social care

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. 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?*

Nationally agreed outcomes are important and a tight focus is needed along with an exploration of the various pathways of achieving them. Often outcomes are broadly drawn and the Alliance believes that change is most likely to arise from specific and measurable outcomes, such as those demonstrated in HEAT targets. We note that there are no similar targets for local authorities and feel that it will be important to ensure that there are national mechanisms in place to monitor performance in way similar to HEAT targets.

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

Yes the Alliance agrees that this would be helpful in supporting consistency across Scotland. We reiterate the need for measurable targets as outlined above.

Governance and joint accountability

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 Neurological Alliance of Scotland believes that the third sector should be a partner in joint commissioning and locality planning and therefore must be a voting member of health and social care committees. The Alliance believes that the proposals should reflect a stronger strategic role within health and social care partnerships for third sector organisations who are a major provider of services as well as having a role in facilitating the involvement of service users in HSCPs. Whilst we acknowledge Scottish Government may have concerns about accountability and capacity within the third sector we believe it important that such a strategic role should be fully explored.

The Alliance do not feel in a position to be able to determine appropriate levels of accountability but would welcome clarification on how any disagreement between local HSCPs and central government would be resolved. We are also interested to know what would happen if the third sector is not in agreement with the Health and Social Care Committee. Are their views disregarded due to not have voting rights and an agreed strategic role? The Alliance believes that consultation with the third sector should be mandatory.

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

The Neurological Alliance of Scotland believes there should be scope to establish a regional HSCP if this would reduce inequalities in service delivery and charging. However there will be issues regarding governance when more than one local authority is involved and resources issue for NHS boards which cover a significant number of local authority areas. It would be important to see how joint accountability will be maintained if regional HSCPs are established.

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

As stated previously, the Alliance believes that the proposals should reflect a stronger strategic role for the third sector within HSCPs. There is a risk of voluntary sector input being tokenistic due to not having voting rights along with NHS board and local authority elected members. At the very least there should be safeguards in place to prevent service providers influencing outcomes in favour of their own services and the legislation should include a duty to consult with voluntary sector organisations and service users.

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?

The Alliance is concerned that the proposals do not describe fully how the Scottish Government plans to scrutinise and hold HSCPs to account. We would like clarification on the processes inherent in deciding when an HSCP has reached a 'critical' point and what intervention is required. It is difficult to comment on the proposed performance management arrangements without know what the triggers would be to initiate voluntary or enforced performance support.

The Neurological Alliance of Scotland has recently worked closely with Healthcare Improvement Scotland in the improvement and support programme for the implementation of the Clinical Standards for Neurological Health Services ¹. Our experience in attempting to accurately capture the performance of NHS Boards has not been hugely encouraging. The Alliance wonders what kind of task force would be involved in delivering performance support beyond simply reviewing performance. For example, would the Care Inspectorate and Healthcare Improvement Scotland also have a role in tackling improvement measures for HSCPs failing to perform satisfactorily and would these agencies be funded appropriately to enable this?

The Alliance also questions what role the third sector would have in reporting on the effectiveness of HSCPs. The third sector makes a valuable partner; offering expertise regarding the needs of its service users, acting as an advocate for its service users and facilitating direct user involvement. We feel it is important for the proposals to set out a clear mechanism by which services users can give feedback about their integrated care and report experiences and complaints. We would therefore like more detail about how service user feedback links into the performance management process.

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?

The impact of neurological conditions are far reaching and the Neurological Alliance believes that there is a strong argument for including aspects of Local Authority housing budgets within the scope of HSCPs. We believe that the Scottish Government should take a prescriptive stance regarding this due to housing issues being a key overlap with both health and social care. Housing issues are also an integral part of the transition from child to adult health/care services and from adult to older people's health/care services. We believe that HSCP's should have the freedom to include the budgets for other CHP functions as they choose.

Integrated budgets and resourcing

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?

¹ NHS QIS (2010) Clinical Standards for Neurological Health Services. NHS Quality Improvement Scotland

The Neurological Alliance of Scotland has concerns that in a time of budget reductions, integrated budgets do not reduce access to specialist care that is crucial for many people with neurological conditions, particularly those that are progressive and complex. People with neurological disease require care from a range of health and care workers with a specialist understanding of their condition. It will be crucial that access to this specialist care continues and is not reduced by HSCPs in favour of providing cheaper services.

The Alliance is also concerned that there is no reference within the proposals to how a 'free at the point of access' NHS service will be integrated with a chargeable social care system. Many neurological conditions are long term and fluctuating and current social care eligibility criteria does not take typically account of this. There is potential that new structures could increase the risk of people with neurological illness finding they are unable to access support across health and social care due to eligibility criteria that does not take account of the nature of their long term condition. The Alliance would encourage the involvement of service users in fairly and effectively addressing these issues.

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?*

The Neurological Alliance does not work directly with individuals. Our member organisations providing a consultation response are therefore better placed to illustrate their experiences on behalf of service users.

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?*

The Neurological Alliance of Scotland does not feel qualified to answer this question and feels that the amount of local discretion HSCPs will have depends on how prescriptive Ministers are.

Jointly Accountable Officer

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?*

The Neurological Alliance of Scotland is not in a position to respond to this question.

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

The Neurological Alliance of Scotland is not in a position to respond to this question.

Professionally led locality planning and commissioning of services

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

The Neurological Alliance of Scotland believes that Scottish Government should provide direction on how locality planning is taken forward to ensure consistency in service provision and avoid inequalities in care. This may also help to ensure that Managed Clinical Networks are able to input to planning groups and will facilitate sharing of practice between HSCPs.

The Alliance believes that guidance should also be provided to locality planning groups on handling parts of the acute budget in order to ensure that there is enough acute specialist resource to respond to the needs of those with complex neurological conditions.

The Alliance also has concerns that many neurological conditions have low prevalence and so may be overlooked in smaller locality groups. Whilst prevalence may be low, people with neurological conditions such as Parkinson's, Huntington's and Motor Neurone Disease are very significant users of health and care services and it is crucial that their complex and sector crossing care needs are met by all localities.

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?*

The Alliance welcomes this proposal but believes that it should be extended to include professionals from the third sector, since it forms an integral part of service provision. We would also want to see meaningful involvement from service users.

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?*

The Alliance wonders if consideration could be given to participation through the Managed Clinical Networks existing at local level which in turn may incentivise MCN involvement.

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

The Alliance has concerns that GP engagement with voluntary organisations over neurological conditions is often variable and sometimes poor. We feel that this can be reduced with closer third sector involvement in locality planning to ensure that the needs of patients and service users are effectively heard and addressed.

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

The Neurological Alliance of Scotland reiterates the need for consistency and would have concerns about the risk of variation in service provision if service and planning are significantly devolved.

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?

As mentioned previously, the Alliance has concerns about commissioning for lower prevalence neurological conditions in small populations.

Do you have any further comments regarding the consultation proposals?

No

Do you have any comments regarding the partial EQIA? (see Annex D)

No

Do you have any comments regarding the partial BRIA? (see Annex E)

No