

Annex G 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?

Yes No

The questions are proposal specific and therefore not relevant to a discussion about the care requirements of young adults (or children) with complex epilepsy and consequential learning disabilities.

The Muir Maxwell Trust (MMT) is a small Scottish charity that supports children across the UK with complex epilepsy and also their families and carers. On behalf of Scottish families, struggling to cope with epilepsy, we wish to highlight the alarming extent to which this Scottish Government proposal overlooks the complex and extensive needs of the learning disabled with epilepsy. We have therefore endeavoured to complete the Consultation Questionnaire, despite this oversight and its specific focus on the elderly and the infirm, in the hope that we can bring this serious oversight to the attention of the Scottish Government.

By way of further explanation, the focus of the Muir Maxwell Trust is primarily complex epilepsy in childhood with associated life-long developmental delay and behavioural problems. However, the incidence of transition in to adult services in the early teenage years for a number of children, with complex epilepsy, means that young adults are also the charity's concern. In particular, those with long term care needs which in many instances have, to date, been quite seriously and alarmingly neglected. It is our view that young adults with epilepsy causing learning disabilities, in addition to complex health needs, represent a burden on society that so far both the UK Government and the Scottish Government have been largely unable to address. In many instances the full extent of the needs of the young adult with epilepsy and learning difficulties fail to be identified and also the needs of the family supporting them. Whilst a few are successfully cared for in the community and some in institutional care, there is a deep rooted fear by parents of inadequate care provision that will compromise the well-being of their child. Therefore, rather than risk compromised care, parents are often inclined to carry the burden of care themselves by opting for their child to continue living at home on a long term, full-time basis.

A young adult with epilepsy and learning difficulties living at home is often considered 'cared for' by the local authorities and whilst parents 'muddle through' and 'struggle on', the arrangement takes its toll on both the young adult and the parents as carers. Both become increasingly isolated and as ageing parents fail to cope, care is in the end compromised. Neither the young adult nor the parents enjoy a fulfilled life.

Until such times as needs are properly and formally assessed for our young adults with epilepsy and learning disabilities (and also in childhood) and financial provision is ring - fenced to meet those needs, it is our view that their care will always be compromised, primarily as a consequence of a lack of awareness of this needy group within the care system. There is a tendency within social services to avoid recording unmet need because of the finite amount of funds available. Ideally, parents should be filled with confidence that their child's long term care needs can be met either in the community or in a form of institutional care (which-ever is more appropriate for their needs), allowing both to enjoy a happy and fulfilled life but the reality is far from this ideal. Whilst many parents would love to look after their children at home it is neither practical nor possible because of their profound and complex learning difficulties.

We have therefore taken this opportunity to highlight the omission of this important group from this proposal and invite the Scottish Government to specifically consider the needs of this group in light of this proposal for integration of adult health and social care, which as written is not practical nor helpful for young adults with epilepsy and learning disabilities.

Our comments on the proposal to integrate the Adult Health and Social Care, from the perspective of

young adults (and children) with complex epilepsy and learning disabilities, are therefore as follows;

The proposal fails to differentiate or consider the specific longer term health and care requirements of young adults with epilepsy and complex learning disabilities but instead prioritises the elderly first, followed by adults with health and social care needs. Whilst elderly people with urgent health/care needs are a priority, so should the very different needs of our young adults with severe epilepsy and learning disabilities who are amongst the most vulnerable in our society and do not have a voice of their own - many suffer from the brain disease known as aphasia. Unlike care for the elderly or the infirm, their care needs are 'life- long' and represent a particularly hefty financial burden on local authority purses. The care needs of young adults with severe epilepsy and learning difficulties are a matter of urgent concern to parents and carers, especially in these times of austerity when funding is limited. With a finite pot of available funds, why therefore are the needs of young adults with learning disabilities the last to be considered in terms of the priorities outlined in this proposal? Surely the quality of care will yet again be limited by the available budget remaining, taking us no further forward than we are at present? The result being that many parents will continue to look after their children at home, with the consequences for both already described above.

It is a sad fact of this disease that some young adults with epilepsy and learning difficulties cannot be supported easily in the community, indeed they cannot relate to the community. The proposal refers to but does not define the scope of the 'institutional care' that the Scottish Government aims to reduce in order to free up funds for more care in the community. Some institutional care works well. New forms of institutional care are emerging and are the very life line we require the Government to develop in order to make young adults with learning difficulties feel safe and ensure that their lives are fulfilled within a community and peer group that they can relate to and know and understand. An attempt to integrate some young adults with epilepsy and severe learning difficulties in to the community by shifting resources to community based services could result in the disastrous outcome we saw under Margaret Thatcher when she tried to do the same in the 1980's. In those days the learning disabled were to be found wandering the streets, neglected and ignored by a society that simply did not understand them.

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?

Yes No

Whilst the proposal does refer to the requirement for 'robust, trustworthy information and evidence, which is critical to the success of the proposal, it fails to address the inadequacies of the current assessment process which, in many instances, is failing to identify the specific needs of our young adults with epilepsy and learning disabilities and their carers by both the medical profession and social services. Both health and social services are enormously under resourced and sometimes plagued by incompetence and therefore the proper assessment of need is simply not a priority. A Section 23 Assessment under the Children's Scotland Act 1995 is the entitlement of all children with learning disabilities and their families. This, if carried out as a matter of course and competently, could serve as a foundation for an assessment of need in to adult services (a passport). Sadly, this does not happen and therefore the needs of the young adult with epilepsy and learning disabilities either require to be assessed from scratch or they are presumed to be okay or overlooked. Robust trustworthy information by way of assessment is key but must be formalised and become a requirement in law if it is to be reliable.

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?

Yes No

Accountability is important but based on what outcomes? What will be the measure of accountability? Proper assessment of need and a requirement in law to meet those needs would have to be the basis for this accountability for young adults with epilepsy and learning disabilities. A legal entitlement to proper assessment of need would have to be the norm or else identifying these needs will once again be avoided (as is currently the case with Section 23 Assessments under the Children's Scotland Act 1995) in order to avoid recording unmet need which is very much the current state of play.

Accountability of some individuals and officials would also be necessary, rather than departments. The present structure allows individuals to hide behind their department and no one individual takes ownership, responsibility or is ultimately answerable when things go wrong.

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 No

The needs of young adults with epilepsy and learning disabilities and the ability to meet those needs, varies geographically. Nationally agreed outcomes could be harsh in the case of young adults with learning disabilities, unless the young person and their family are willing to transfer to where the needs can be adequately met. It is our experience that services just simply cannot be matched across the country, due to different resources, expertise and financial restraints. We have accepted a concept of 'centres of excellence' for complex conditions such as epilepsy syndromes. Perhaps the same concept should apply for the purpose of this proposal in the context of meeting the needs of young adults with learning disabilities, which would then also favour a place for some appropriate and high quality institutional care. An example of such care might be Young Epilepsy in Lingfield in Surrey where young adults (up to the age of 25 years) with epilepsy and learning disabilities can enjoy appropriate further education on a residential basis with a state of the art medical centre in support. This is most definitely a model worth looking at for Scotland.

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?

Yes No

Accountability is important but based on what outcomes? What will be the measure of accountability? Proper assessment of need and a requirement in law to meet those needs would have to be the basis for this accountability for young adults with epilepsy and learning disabilities. A legal entitlement to proper assessment of need would have to be the norm or else identifying these needs will once again be avoided (as is currently the case with Section 23 Assessments under the Children's Scotland Act 1995) in order to avoid recording unmet need which is very much the current state of play.

Accountability of some individuals and officials would also be necessary, rather than departments. The present structure allows individuals to hide behind their department and no one individual takes ownership, responsibility or is ultimately answerable when things go wrong.

We are also concerned that with joint accountability there is no independent assessment regarding the needs of this group of young adults. Currently, Community Learning Disability Nursing Services assess needs and their task is not budget driven. It is our experience that assessment by Social Services often omits needs that cannot be met because of budget restraints.

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

Yes No

A partnership covering more than one Local Authority would presumably also be jointly accountable. As the needs of young adults with epilepsy and learning disabilities and the ability to meet those needs, varies geographically, a partnership covering more than one Local Authority could be harsh in the case of young adults with learning disabilities, unless the young person and their family are willing to transfer to where the needs can be adequately met. It is our experience that services just simply cannot be matched across the country, due to different resources, expertise and financial restraints. We have accepted a concept of 'centres of excellence' for complex conditions such as epilepsy syndromes. Perhaps the same concept should apply for the purpose of this proposal in the context of meeting the needs of young adults with learning disabilities, which would then also favour a place for some appropriate and high quality institutional care. An example of such care might be Young Epilepsy in Lingfield in Surrey where young adults (up to the age of 25 years) with epilepsy and learning disabilities can enjoy appropriate further education on a residential basis with a state of the art medical centre in support. This is most definitely a model worth looking at for Scotland.

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

Yes No

Good governance by any committee requires accountability but again, based on what outcomes? What will be the measure of accountability? Proper assessment of need and a requirement in law to meet those needs would have to be the basis for this accountability for young adults with epilepsy and learning disabilities. A legal entitlement to proper assessment of need would have to be the norm or else identifying these needs will once again be avoided (as is currently the case with Section 23 Assessments under the Children's Scotland Act 1995) in order to avoid recording unmet need which is very much the current state of play.

Accountability of some individuals and officials would also be necessary, rather than departments. The present structure allows individuals to hide behind their department and no one individual takes ownership, responsibility or is ultimately answerable when things go wrong.

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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?

Yes No

Public confidence in our ability to provide and care for young adults with epilepsy and learning disabilities will only come from a proper foundation of assessment of need that accurately identifies need and endeavours to meet it appropriately. Currently, families are fearful of the quality of care that can be provided and therefore frequently opt for more control of that care themselves by either keeping their child at home or opting for self-directed support, if offered.

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?

Yes No

No comment

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?

Yes No

Currently, the health service (Community Health Disability Nursing Services) in its role as assessor of the needs of young adults with learning disabilities is not restricted or answerable to a budget. In theory, the needs should therefore be fully and properly identified regardless of budget, although that is not to say that the needs will be/can be met by social services.

Under the proposal, if both health and social services are restricted by a budget and must identify the best use of the available budget then by implication, the needs will only be met based on that budget, once again creating an opportunity to avoid recording unmet need unless an accurate assessment process is a requirement in law.

The independent role of the health service in the assessment of needs of the young adult with epilepsy and learning disabilities is therefore gone. We will no longer be directed by need but by best use of budget. This is of great concern for parents whose children have epilepsy and learning disabilities. In particular, there is concern that self-directed support will be under funded whilst the concept is, to some extent, welcome.

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?

Yes No

On this one question we are answering with reference to the direct payment scheme or self-directed support which is how it is referred to in Scotland. Feedback from our parents on direct payments is quite good although, where the system fails to identify the true extent of the need, the direct payments can fall far short of what is required. An additional problem that many of our parents/ carers receiving direct payments experience is sourcing the professional support that they require, particularly in more rural areas. Support falls down during periods of annual leave and sickness leaving parents to fill the gap on their own. Some also struggle with the paperwork that they then have to complete ie time sheets, tax, NI etc, and outsourcing this can be costly. The most successful examples of the direct payment scheme appear to be where young adults are funded to live in their own home with a suitable peer group within the community and where carers are employed by the parents.

The self-directed support scheme does give rise to concerns about the potentially increased number of parents/ carers that are likely to opt for caring for their young adult with learning difficulties at home, ultimately unable to cope themselves and perhaps unsure of the level of need that is required or should be made available to assist them.

The risk of under-funding via self-directed support could prevent parents opting for their young adults to be supported independently in the community in their own homes or indeed, in high quality institutional care, requiring many parents, to care for their young adult with learning difficulties at home and they struggle to cope.

Again, the requirement for accurate assessment of need is the only way to ensure that sufficient funds are made available to adequately meet those needs. It would appear however, that where a patient is made 'a ward of the state', their prospects of long term quality care are not always but sometimes adequately met.

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?

Yes No

Minimum categories of spend are quite dangerous for our young adults with epilepsy and learning disabilities. The risk is that minimum spend becomes the bench mark in a climate that is strapped for cash - unless of course it also has to be needs driven and accurate assessment of need is a requirement in law. Minimum spend categories could well see a return to the 1980's when the learning disabled were to be found wandering the streets, neglected and ignored by a society that simply did not understand them.

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?

Yes No

We consider this question more relevant to the elderly and the infirm but not relevant to our children and young adults with complex epilepsies and learning disabilities who are, for the most part, well cared for within the NHS by the specialists in their appropriate fields. Where the system currently fails them is in terms of educational and social care needs, including respite and particularly over- night respite, be it in the home, in institutional care or in care in the community. The financial provision simply doesn't exist. Ring-fenced funds are the only answer if we are to meet the long- term care needs of this complex group.

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

Yes No

No comment

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?

Yes No

We have minimal confidence in the Local Authority's ability to direct budgets appropriately. Ring fenced funds for each Local Authority determined by Government is the only secure way to manage budget and planning for the requirements of this group of young adults with epilepsy and learning difficulties.

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?

Yes No

Complex epilepsy syndromes are not necessarily understood by generalists such as GP's. Indeed, referrals to some specialist epilepsy centres are discouraged from GP's and will only be accepted from neurologists with a specialism in epilepsy, for example, the Developmental Epilepsy Clinic at GOSH. Whilst some patients and their carers are well supported by their GPs who understand their health and care requirements, many GPs are not the point of contact for their patients and carers who have such complex conditions. GPs do not necessarily have an understanding of the complexities of some epilepsies and therefore fail to understand the level of support that is required. The involvement of local professionals for young adults with epilepsy and learning disabilities could therefore mean that they are vulnerable to inadequate care due to a lack of specialist knowledge of complex epilepsy syndromes which in most cases is inclined to be patient specific. We should highlight at this stage that there are at least some 40 different kinds of epilepsy and a similar number of seizures and much about epilepsy is still not understood.

Currently this role is fulfilled competently by the Community Health Disability Nursing Service, where proper assessment is carried out but relies on the co-operation of Social Services.

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?

Social Services require to be substantially expanded with a much reduced dependency on part - time female employees. These enormously under resourced departments populated largely by part- time female social workers has resulted in a most disjointed service, with frequent long periods of absence due to illness, maternity leave and extended periods of annual leave.

Continuity is essential for young adults with epilepsy and learning disabilities if their needs are to be accurately assessed and met and then monitored. In many instances, Social Services departments are failing to fulfil their own statutory obligations with gaping holes in their records as over stretched and deeply stressed part - time employees fail to cope with their work load. All too often parents and carers are given the impression that social workers are there to represent and look after the interests of the Local Authority and their budgets, rather than the immediate and long term needs of the young adult with epilepsy and learning difficulties.

At the end of the day no one within Social Services is called to task when a young adult with epilepsy and learning difficulties suffers, everyone taking cover behind 'the Department.' An expanded department with a sensible balance of males/ females and part- time / full- time workers is essential if Social Services is to function properly. Proper formal assessment of need in law remains the key.

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

Yes No

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Currently this role is fulfilled competently by the Community Health Disability Nursing Service, where proper assessment is carried out but relies on the co-operation of Social Services.

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

We consider this question more relevant to planning for care for the elderly and infirm.

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?

Yes No

No comments

Do you have any further comments regarding the consultation proposals?**IN SUMMARY**

The proposal fails to address the specific requirements of young adults with complex epilepsy and learning disabilities. This group appears to be last in the queue and by definition, a low priority.

There is a risk that the proposal will result in many more young adults with epilepsy and learning disabilities remaining at home in the care of their ageing parents with inadequate financial resources to meet their needs.

The proposal states that proportionally fewer resources will be directed towards institutional care, favouring community provision and capacity building. There is still a place for appropriate, high quality institutional care. The scope of institutional care referred to by the proposal requires to be defined.

Self-directed support will result in more parents caring for their young adult epilepsy and with learning difficulties at home themselves and where the self-directed support payment is inadequate, they will struggle to cope.

Not all but some patients who are made a ward of the state sometimes receive adequate care.

Robust, trustworthy information and evidence by competent individuals will be critical to the success of the proposal - but this is lacking to date. Who will carry out these assessments and will they be based in law? Will they be carried out by an independent assessor?

GPs are too generalist and should not be relied upon to direct and deliver community care for young adults with complex epilepsy and learning disabilities.

Social Services have a fuller role to play but will require to be adequately and more appropriately resourced with an emphasis on proper assessment of need which ideally should be a requirement in law.

Community Health Disability Services currently act as an independent assessor of need of young adults with epilepsy and learning disabilities. It would be dangerous to make them budget driven and remove their independence.

Ring- fenced funds are an essential requirement for young adults with learning disabilities. Without ring-fenced funds the majority in this group are most likely to be marginalised.

A long-term passport to care requires to be identified - perhaps a Section 23 Assessment under the Children Scotland Act 1995.

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

No comment

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

No comment