



Consultation response: Integration of Adult Health and Social Care from the Independent Living in Scotland project (September 2012)

This response has been prepared by the Independent Living in Scotland (ILiS) Project Team on behalf of the ILiS Steering Group.

It has been prepared with the assistance of a disabled people who contributed evidence to ILiS, Inclusion Scotland, Scottish Disability Equality Forum, the Glasgow and Lothian Centres for Inclusive Living, Glasgow Disability Alliance and Self-Directed Support Scotland. It is based on a response prepared by Inclusion Scotland.

Introduction

1.1 The Independent Living in Scotland project (www.ilis.co.uk) aims to support disabled people in Scotland to have their voices heard and to build the disabled people's Independent Living Movement (ILM)¹. It is funded by the Scottish Government Equality Unit as part of a wider Government initiative on independent living. It is hosted by Inclusion Scotland, a consortium of Disabled People's Organisations and steered by a group of disabled people².

(DPO's are organisations led by and for disabled people. You can find out more about them in the ILiS publication "It's Our World Too", available at www.ilis.co.uk.)

1.2 The ILiS project is part of the wider Scottish Government Independent Living Programme which seeks to mainstream the principles and practices of independent living within the general economic and social policy of Scotland. The Scottish Government's commitment to independent living is set out in the "Vision for Independent Living" (<http://www.ilis.co.uk/independent-living/a-vision-for-independent-living-in-scotland/>). This Vision was co-signed by Scottish Ministers, CoSLA and NHS Scotland, alongside the Independent Living Movement.

¹ <http://www.ilis.co.uk/>

² Although ILiS project is not a disabled people's organisation per se, it is steered by a coalition of disabled people's organisations and other organisations that promote the principles of independent living.

1.3 The definition of independent living developed by disabled people and adopted by the ILIS project is;

“disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”.

With such support, disabled people can exercise their rights and duties of citizenship via their full and equal participation in the civic and economic life of Scotland – thereby changing the public misperception of them as being a drain on society’s resources rather than an active contributor.

The principles of independent living, ***freedom, choice, dignity and control*** not only relate to those services and provisions specific to disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities; policies and structures, affecting every aspect of quality and equality of life³: These principles are underpinned by the following basic rights and areas of support. Without these, the principles of freedom, choice, dignity and control cannot be realised.

³ ILiS; “The Essential Guide to Independent Living”, 2009

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance
- Inclusive education and training
- An income, including income within the state-benefit system for those unable to work
- Equal opportunities for employment
- Accessible and readily available information
- Advocacy and working towards self-advocacy
- Counselling, including peer counselling
- Accessible and inclusive healthcare provision
- Communication and appropriate support for communication
- Civic participation

1.4 We are grateful for this opportunity to respond to this consultation on the development services which are of critical value to disabled people. This response to the Scottish Government's consultation on the Integration of Adult Health and Social Care draws on evidence gathered by ILiS, Inclusion Scotland, Scottish Disability Equality Forum, the Glasgow and Lothian Centres for Inclusive Living, Glasgow Disability Alliance and Self-Directed Support Scotland. This evidence was gathered from disabled people across Scotland throughout summer 2012. The following response therefore represents the views of many

disabled people and their Organisations.

ILiS gratefully acknowledges the assistance of all the above organisations and in particular, Inclusion Scotland who led on the preparation of a coalition response on behalf of all the above mentioned organisations. This response is based on that coalition response.

1.5 As one of a group of organisations representing disabled people, a description that fits many older people and the group most likely to use the planned for integrated services, we hope that there will be scope for our continued involvement and opportunities for coproduction of future regulation, policy, service development and delivery, guidance and monitoring.

1. **Overview**

2.1 Disabled People and their organisations broadly support the aims of the integration of health and social care agenda as we feel this has the potential to offer seamless, preventative care and support in a more efficient way. There is wide recognition that the current situation is not sustainable, in particular due to our ageing population.

2.2. Disabled people, supported by the organisations listed above, produced a document called 'The 5 asks of disabled people' (available to download here: <http://www.ilis.co.uk/get-active/independent-living-policy/health-and-social-care-integration/>). These 'asks' are explored in the following consultation.

In addition, ILiS also supports the wider messages on health and social care integration contained in the Long Term Conditions Alliance Scotland's 'Shared Statement from the third Sector'. – available to download here: <http://www.ltcas.org.uk/resources/library/>

2.3 ILiS supported events led by Inclusion Scotland to consult with disabled people. In addition, the consultation was widely distributed to disabled people who could not attend events in person and their views have been incorporated into this response. Consequently, this response represents the representative views of well over a thousand disabled people.

3. The case for change

3.1 Independent living often fails when services do not work together to ensure seamless support and provision⁴. Disabled people believe that joined up working and preventative spending should be a key feature of service delivery in health and social care and see integration as a unique opportunity to provide disabled people with the seamless services we require to realise independent living.

3.2 For this reason, we have identified many of the same potential advantages as the Scottish Government, such as meeting the needs of our ageing population and freeing up health funding to go towards social care (where funding is increasingly limited due to local authority budget

⁴ ILiS; 2011, "ILiS response to the JCHR report on the implementation of Article 19 of the UNCRPD"

cuts).

However, it is important that the funding transfers meet the overarching objectives of integration and are not diverted to cover other funding shortfalls. The deployment of funding, and other resources, needs to be flexible and targeted towards meeting the end aims and not the system needs. Essentially, this means that the money needs to follow the person and not the service. Ultimately, it is the realisation of independent living outcomes for humans which will verify that the changes have been successful.

We recommend therefore, (**Recommendation**) that funding must follow the individual rather than be swallowed by the system and that it should not be used to address funding shortfalls e.g. in the acute health budget.

4. Recommendations for successful integration of adult health and social care

4.1 ILiS and its peer organisations produced the ‘asks’ document (see section 2.2 above) following in-depth consideration of the proposals for integration.

The ‘asks’ highlight the things we hope the Government will take into account when progressing this agenda.

Ask 1: That the principles and outcomes of health and social care integration support independent living, citizenship and human rights.

Ask 2: Disabled people must be considered, respected and supported as key stakeholders and co-producers in the development and delivery of integrated health and social care and they are ready, willing and able to this.

Ask 3: It is important that disabled people, other users of the integrated systems and the wider Third sector, are involved in leading, not just on the principles of an integrated system, but on how money within it is spent, including; eligibility to access it, assessment for it, and principles for its use.

Ask 4: It is important that all the views of all users of health and social care and not just older people, are considered during the early stages of integration, so that the changes brought about are in line with their expressed needs and their rights.

Ask 5: Self-directed Support (SDS) and integrated health and social care service must work together – not move apart: the SDS Bill should be extended to include health funded support in the community for the person when they ‘exit’ hospital based services.

In greater detail, this means:

4.2 Ask 1

That the principles and outcomes of health and social care integration support independent living, citizenship and human rights.

We believe the present plans are too focussed on health and on organisational outcomes; rather than those of the end user. Outcomes should be around the principles of independent living and the contribution the person can make to society as full and equal citizens. The definition of independent living and the Basic Rights, as developed by disabled people and their organisations, helps to explain this (see 1.3 above).

Recommendation 1: The integration of health and social care therefore, should be underpinned by principles of human rights, independent living and citizenship with outputs and outcomes that support these principles for the end user. This supports the preventative, more cost effective approach to service delivery recommended by the Christie Commission.⁵

The experience of Northern Ireland shows that the health agenda can dominate the delivery of integrated health & social care services, placing the onus on organisational outcomes resulting in medical rather than social outcomes for disabled people. Crucially, it also means that the joined up approach needed for independent living is sometimes missed and that there is little room left for Self Directed Support (SDS) outcomes⁶. For these reasons we are encouraged to

⁵ Christie Commission (2010) "Report of the Christie Commission on Public Sector Reform"

⁶ See Heenan D and Birrell D (2006) The integration of health and social care – the lessons from Northern Ireland, *Social Policy and Administration*, 40, 47-66; and Heenan D and Birrell D (2009) Organisational integration in health and social care: Some reflections on the Northern Ireland experience, *Journal of Integrated Care*, 17, 5, 3-12

see that independent living is one of the outcomes in the proposals for integration.

We hope that the Scottish Government will use the definition of independent living provided by the ILiS project (see 1.3 above) for this purpose as it fully takes on board the rights of disabled people to practical assistance to live an ordinary life. A large part of the practical assistance disabled people need to live independently comes from their health and social care services.

Whilst we acknowledge that measuring health improvements is much easier than, say, measuring individual realisation of freedom, choice, dignity, and control, it will be important for the Scottish Government, health boards and local authorities to find ways of measuring and monitoring independent living outcomes. The starting point for this will be ensuring that people understand what it means.

Disabled people at the consultation events pointed to examples in which disabled people/service users had been employed to monitor the achievement of outcome including an example relating to the Care Inspectorate employing and training disabled people up in monitoring roles. This was seen as a good model that could both lead to increased accountability and robust involvement. DPO's are in a good position to support all stakeholders in devising such methodologies involving disabled people themselves. In addition, Evaluation Support Scotland

are working to develop outcomes and monitoring systems to support Self-Directed Support pilots set up by the Scottish Government and could offer the integration team some potential solutions.

Recommendation 2: we suggest adding ‘and improved well-being’ to the first outcome of healthier living as these are widely recognised as being closely related. Doing this would give equal weight to the benefits of both good social care as well as good healthcare.

The addition of ‘improved wellbeing’ would fit in well with the Scottish Government’s own national outcomes. We believe that well-being is co-dependent on increased access to independent living and inclusion in society.

We also believe that there should be a place in the list of outcomes for service users, particularly as we are considered to be at the heart of these changes.

Recommendation 3: In addition we suggest that an additional outcome is added; ‘high quality services respond to the care needs identified by service users’.

Recommendation 4: Once National Outcomes have been agreed, the integration outcomes should form an integral part of local outcome setting and believe that Single Outcome Agreements would be an

appropriate place to integrate them into wider plans.

We recognise that there is a degree of local control required in order to overcome conditions and local barriers to accessing services. In particular, access to rural health and care services is much more difficult than access to the same services in a city, and as Scotland has large rural areas in which people live, it is important that local rural services are adapted to suit, for example, the terrain and distances involved in accessing a GP. However, we fear a situation whereby local decision making leads to a 'post-code lottery' of provision as this would further embed current barriers to independent living, such as the inflexibility of portability of care policies. For this reason, we feel it is important that a set of minimum standards is agreed so that services users know what they can expect nationally across the whole system.

BME and transgender disabled people face additional barriers to independent living and to services as they are generally not appropriate to their needs.⁷ They are more likely to experience discrimination when accessing services.

Recommendation 5: it is crucial therefore that all practitioners get diversity training regularly in order to achieve the outcomes for all service users.

⁷ Inclusion Scotland and Glasgow Disability Alliance supported Equality Network to do research on how disabled LGBT people access services and what their barriers are to receiving quality services. The research report is forthcoming.

We heard many stories of services that did not meet disabled people's needs. For example, social care all too often addresses basic needs such as washing, feeding, dressing etc. when what is needed in addition to personal support is support to be involved in the community.

Whilst we view the move to discharge people from hospitals at a suitable time positively, disabled people are all too aware of the importance of having a suitable care package in place. We believe the importance of proper investment in community care is absolutely crucial and that this must take account of appropriate timeliness and that disabled people should not have to undergo prolonged and non-health related hospital stays.

Sending people home without a care package will result wider issues, affecting multiple people. One participant explained that on return from hospital she was told to ask her sister to move in with her. She felt this was entirely inappropriate as she had never lived with her sister as an adult and it would put strain on their relationship; her sister would have additional responsibility; her home would no longer be her own and it would curtail her independence. This was the only option she was offered.

At the moment information on provision and entitlement is not widely and appropriately available to people being discharged from hospital. Such information would need to take account of (and perhaps inspire)

increased joined-up working practices.

Recommendation 6: sufficient investment needs to be made to provide information to people returning home from hospital on what services are available to them and what they are entitled to.

We would suggest that were the outcomes for integrated service to support independent living this would mean inappropriate solutions, or crisis, life and limb intervention would be avoidable and instead, a more preventative and appropriate approach to meeting people's needs will be developed.

4.3 Ask 2

Disabled people must be considered, respected and supported as key stakeholders and co-producers in the development and delivery of integrated health and social care and they are ready, willing and able to this.

Disabled people and their organisations are ready, willing and able to help shape this agenda. They want to work in partnership with the NHS, Scottish Government, Local Authorities and the third sector to support the development and maintenance of an effective integrated health and

social system in Scotland.

DPO's have many members who, as citizens and in some cases as users of health and social care, can help to ensure this agenda is fit for purpose. Through their organisations, disabled people have supported the strategic development of policy and practise in many areas in Scotland, e.g. "Self Directed Support" agenda, and so have valuable experience to bring to this integration process.

In addition, DPO's will work with our colleagues in Northern Ireland who can provide us with examples of what works well and what doesn't, for disabled people, in their experience of integration. We will ensure that the experience from Northern Ireland is passed onto the Scottish Government and to disabled people involved in local partnerships so that they may learn from it. We are certain that this could lead to partnerships avoiding many potential pitfalls that stand in the way of a truly successful integration of services.

We also feel that increasing professional leadership should be balanced with an increase in service-user leadership. Professional-only led integration will simply continue to promote the same power relations as have endured till now. As People First said - "we need a voice at the highest level" . The recommendation of the Christie Commission is for co-production with service users and not top-down decision making.

Disabled people in Scotland support the recommendations of the Christie Commission report on the future of public services; some of us were involved in setting those recommendations through the Commissions coproduction. For integration to embrace the vision set out in the consultation these principles and recommendations should be much more thoroughly embedded within these proposals, so that they are clearly defined and given prominence within the legislation.

Co-production is “an approach that recognises the value of partnership between disabled people and public authorities in developing services, policies and strategies”⁸. DPO’s should be seen as full and equal stakeholders and co-producers in the integration of health and social services, including and especially at decision-making and strategic level. They have a right to influence meaningful health and social service outcomes⁹ and to be heard within policy and service planning, design, commissioning and monitoring, right through to evaluation and revision.

Recommendation 7: the plans to integrate health and social care should be coproduced with users of it. This needs to mean real coproduction, where service users are supported to be involved in decision making at every level and not merely consulted on decisions already made by those in authority or invited to use a share of assets to respond to a need or shortfall, on a local basis only.

⁸ Evaluation of Local Housing Strategies Co-Production Pilots, Scottish Government 2011

⁹ The Equality Act (2010), The UNCRPD Article 4 (2009)

As a key part of the process, Community Health (Care) Partnerships should involve disabled people in policy and service development for the set up and delivery of the integrated system, and support them to do so. This will help to ensure that the system delivers its intended outcomes including a system that is efficient and appropriate.

Recommendation 8: Community Health Partnerships should involve disabled people in their work in the integrated system and support them to do so.

As full and equal stakeholders, disabled people must be offered due respect and consideration in the development process. This means they should get the most appropriate and adequate amount of support to make their participation effective and meaningful and so that they can act as a conduit for the views of other service users. This will also involve increasing the role of advocacy in order to support fair exposure and participation in complex and unfamiliar subjects.

People First Scotland has said “We need more control, to be listened to, taken seriously and respected”. Well-funded and widely available advocacy services would help to ensure delivery of the most appropriate and high quality support to those who need it. Good advocacy should also be seen as a preventative spending adding value to the flexible and efficient joint working the SG wants to achieve. Where there is insufficient advocacy, poor quality, ill-timed, inconsistent and/or

inappropriate health interventions or care services may occur leading to inefficiency through, for instance, increased reliance on mental health services or additional health interventions due to anxiety.

Recommendation 9: access to advocacy to support access and participation to coproduce the system and its development and delivery should be increased.

Disabled people have cited a strong need for accountability of elected officers, the CH(C)Ps and joint budgetary officers; and for transparency. To see a real change in the outcomes achieved as a result of redesign of these services all the decisions to date should have been made with full involvement of service users, including disabled people.

Recommendation 10: that in addition to committing to co-producing integration with service users, joint accountability to the Scottish Government includes evidence that co-production is taking place in meaningful ways.

The above evidence should show that neither field is dominating the integration. Transparency and local accountability should be ensured immediately on integration so that this evidence is easily available and service users can monitor how effective the change has been.

In addition to this, an in-depth understanding of Disability Equality will be needed by professionals. In 2006/7 inclusion Scotland surveyed its members on their experience of the NHS. The results showed that they experienced a lack of sensitivity and understanding of their health care needs from all areas of the health service from primary through to acute care. At the events set up to gather evidence for consultation response, participants said that the success of social support provided often depended on individual social workers. It is equally important that leaders, managers and others at policy level share that understanding. The training should be given by disabled trainers and include educating practitioners on the accepted models of disability and their application in real life. DPO's are well placed to provide or signpost to good quality disability equality trainers.

N.B. Disability Equality Training is not the same as Disability Awareness Training. Disability Awareness Training is insufficient to enable a true understanding of how to support the inclusion of human rights, independent living and citizenship throughout services, whereas Disability Equality Training considers these issues in depth. It is for these reasons that we specifically recommend DET.

DET may help to ease a very necessary culture change as it a commonly accepted view of disabled people that medical staff tend to view disability as being entirely about the effects of the impairment on the individuals body and capabilities. On the other hand, understanding

disability from a social model perspective, which supports independent living and a human based approach, is about preventing 'disability'; supporting the removal of the multiple barriers that disabled people face in all areas of their lives.

In many examples provided by participants at our events, it is clear that only medical and clinical intervention or an approach that seeks only to prevent impairment yet fails to recognise the significant barriers that exist, is on offer.

Recommendation 11: training and awareness on disability equality and independent living, on an on-going basis..

In addition to securing robust accountability mechanisms, it is important that people can challenge decisions, individually and collectively. Disabled people are less likely to complain or appeal a decision when things go wrong (than non-disabled people) because they feel they might lose what support they receive. Therefore we make recommendations for an advocacy to support early, service level challenge and also for a tribunal system.

Recommendation 12: good quality independent advocacy is provided to support disabled people to challenge decisions about themselves.

Recommendation 13: An independent tribunal system in Scotland for all health and social care decisions would provide disabled people with a route to appropriate redress and would give people confidence to challenge damaging and inappropriate decisions.

8. Ask 3

It is important that disabled people, other users of the integrated systems and the wider Third sector, are involved in leading, not just on the principles of an integrated system, but on how money within it is spent, including; eligibility to access it, assessment for it, and principles for its use.

The integration of health and social services will necessarily throw up questions around the funding of it in terms of; what is health care and what is social care, what is currently chargeable (via LA's) and what is not (via the NHS). Achieving the outcomes in one part of the system, e.g. 'to unblock beds', may result in a greater spend in another part of the system, or it could result in savings. Therefore it is important to plan for what happens when savings are made (e.g. through less duplication, more targeted outcomes etc.) and for disabled people to be part of that discussion.

Recommendation 14: the wider issues of funding for health and social care should be determined together with the end users of health and social services.

In addition, it is crucial that the systems developed to control, assess for, distribute and determine eligibility for the integrated systems, must not be developed as rationing tools but as tools to support independent living, citizenship and human rights and must be based on the principles and practices of independent living.

Recommendation 15: the tools to be developed to support the integrated systems must be based on human rights and the principles and practices of independent living.

Our event attendees were encouraged that a more flexible approach will be taken to spending health and social care budgets. However many recognised that preventative spending is very difficult to put into practice. In particular, preventative spending would have to be person centred and unique to each service user.

Recommendation 16: flexible spending, which puts the service user at the centre, is developed throughout the integration.

An example underpinning recommendation 18 would include letting people choose how they space different health appointments, where possible, so that money can be saved on taxi fares. This shows how simple solutions sought by individuals could save money for the greater good. Even if saving money is not an aim of the bill, and we are glad it is

not, having that positive impact on the budgets of both service users and Scottish Government can only be a positive result.

Whilst we are aware that in integrating existing services some initial money will need to be spent to re-align them so that they can work in a joined-up way, we believe that as much of the available financial resources as possible, needs to be spent on service-users. This means that there is a need to ensure that outcomes such as 'effective resource use' are aimed at improving service delivery for service-users and not primarily for organisational gains.

Disabled people who attended our events struggled to anticipate how money saved in reduction of hospital bed use, for example, is going to be translated into community care spending and not merely become a saving in health spending.

There needs to be an evidence trail to demonstrate that the above (or an alternative) has happened; to show where the money has gone to. There needs to be sufficient regulation to allow strategic commissioning bodies to identify spending on service-users in an outcome based way rather in a purely quantitative way.

Recommendation 17: that funding follows the individual rather than be swallowed by the system and that it should not be re-directed to address funding shortfalls e.g. in the acute health budget (and that evidence is

required to demonstrate this output).

Recommendation 18: regulations allow for strategic commissioning bodies to identify savings achieved and subsequent spend on service-users, plus, where appropriate, preventative spending vs future spend.

Despite the benefits of using money differently, there is a lot of anxiety amongst our members that not putting additional funding into the system and with money spent on setting it up it might mean less is available for health and social care. Whilst the two models of budget management proposed have the potential to integrate the money in a way that ensures that joint spending goes where it is needed, we are concerned that not putting additional funding into the system will mean that services will continue to fail to meet the needs of users, as documented in various reports, including the report of the Joint Committee on Human Rights¹⁰.

This is particularly important as merely using existing resources differently leaves disabled people open to the politics of majority. For example, the level of disinvestment needed in some services will require a strong public narrative to support it. We have already seen major cuts to social care provided by local authorities because of their own decreasing budgets. Disabled people want to see money being directed into community care where it is urgently needed.

¹⁰ Joint Committee on Human Rights; 2001; "Report of the JCHR into the implementation of Article 19 of the UNCRPD"

However, as the voice of disabled people is seldom heard, this is sometimes overlooked and because it is a minority voice, support for that voice, which is about human rights, may not be universal. Consequently, it is important that disabled people are supported to engage in local decision making in such a way that their needs are recognised and supported in the narrative around investment.

Recommendation 19: disabled people are supported to engage in local decision making in order that their needs are recognised.

We would subsequently highlight that it is crucial that decisions around budgets, in particular decisions on process vs outcomes, are balanced carefully when dealing with a finite budget and that to do this disabled people should also be at the table in making these budgetary decisions. Participants at one of our events

9. Ask 4

It is important that all the views of all users of health and social care, and not just older people, are considered during the early stages of integration, so that the changes brought about are in line with their expressed needs and their rights.

The integration of health and social services is complex and it is important to start somewhere. However, it is also important to

understand that whilst older people generally come into the health and social care systems because they have an impairment or long term condition, their views, aspirations and expectations may differ from those of younger and working age disabled people.

Therefore, it would be detrimental to other end users if the integrated system were simply designed around the outcomes for one particular group. Whilst many of the outcomes of older and working age people are the same – to enable choice and control over one’s own life – many are different – younger disabled people may like to consider starting a family or progressing a career in ways that older people may not. It is important that needs and input of all future users of health and social care are considered at the early stages of integration, before systems and processes become entrenched around the needs of just one part of the community, so that they may be fit for purpose in the longer term.

Many young adults recounted that the transitions from school to college/work and from family home to independent living had not been supported if at all; both health and social care seemed to drop off suddenly at a time when it was most needed.

Recommendation 20: There needs to be age-specific focus built into the systems for integration, to address specific times of life e.g. transitions from school.

Regardless of whether the plans proceed for a wider age range or only for older people, we agree with the Scottish Government that there should be flexibility over the definition of older people rather than a numeric age limit, but we are concerned that the lack of guidance/ clarification may exclude some disabled adults with long term conditions and impairments.

The Scottish Government has identified beneficiaries as those with complex health and social care needs who frequently use services but this can vary and does not necessarily tie to age. For example, mental health service users with perhaps less complex physical needs, might also benefit, due to their reliance on a variety of services at different times.

Recommendation 21: there needs to be further clarity on how those individuals to be subject of for integrated services will be identified and targeted.

The initial focus on older people raises concerns over charges for community care. Over 65's get free personal care in Scotland but disabled people under 65 have to pay for the same services. Charges vary across Scottish local authorities, with very little information available to service users to help them plan, resulting in disparity across the country. Community care charges only 'contribute 4% towards the total budget of local authority social care. However, that same

community care charge can constitute up to 90% of an individual disabled person's disposable income'.¹¹

If people with long term conditions and/or complex needs who are not entitled to free personal care were to benefit from integration, the concern is that they will be more inclined to rely on non-preventative medical health care for treatment at a stage beyond which the condition might have been managed preventatively. In addition to the projected losses disabled people in Scotland face from the UK Government's welfare reforms, difficult choices regarding heating, eating and paying for care are already being made as disabled people have less money to spend on their additional needs because they are paying for the care they need.

This is an absolutely critical issue. It is impacting on the choice, control, dignity and freedom of many disabled people and yet there appears to be a reluctance to address the issue, across the board.

Recommendation 22: community care be free at the point of delivery and a Commission on the funding of social care be set up to consider and implement this.

¹¹ Elder-Woodward, Jim 20 August 2012 'Is it Right to Buy a Right?' Disability Rights Blog, accessed on <http://disabilityrightsblog.wordpress.com/2012/08/20/is-it-right-to-buy-a-right/>

We recognise the value in the aim of robust public involvement but we would like to see more clarity of the extent to which disabled people, ask key stakeholders and service users, will be supported to be involved. We believe that integration needs to involve as many disabled people of all backgrounds and their organisations as possible. In particular, this should extend to all ages and not just older disabled people, because ultimately they too will be participants in the system even though at the outset this will not be the case. It is crucial, however, that the services are designed with all adult ages in mind from the outset.

Recommendation 23: disabled people of all ages should be involved in coproducing the system at the outset of integration so that the services are fit for purpose with the system is extended in the future beyond older people's care.

10. Ask 5: Self-directed Support (SDS) and integrated health and social care service must work together – not move apart: the SDS Bill should be extended to include health funded support in the community for the person when they 'exit' hospital based services

The Scottish Government is to be applauded for their support of the principles of independent living and the practical measures they have taken to extend the use of Self Directed Support. The Scottish Government's SDS strategy makes it clear that service users and professionals are to be considered equal partners in the process and

that the users are active participants in their own support. This must be reflected in the integration. The Independent Living Movement is concerned that the proposed focus of health and social care services places greater emphasis on the professionals' role and on organisational rather than service user outcomes.

The SDS Bill does not include provisions for community based health care. This means that under a system of integrated budgets and where a person 'starts' in the system from within the NHS, there is a concern that they may not be enabled to access their 'community care' using SDS. It is therefore important that steps are taken to integrate the delivery of the SDS Bill with H&SC Integration to include support in the community for the person when they 'exit' hospital based services.

Recommendation 23: steps are taken to align the integration of health and social care with the SDS Bill.

With a person centred, outcome approach some inclusion of self-directed support will be necessary to achieve these outcomes. Everyone at our events were very supportive of the SDS agenda and concerned that if they opted for SDS they might in some way lose out of an integrated care budget if the budget is not available to those on SDS.

Self-directed support was given as an example of a way of working that had disabled people, rather than services and professionals, in a lead role in deciding how money for their care should be spent. They

viewed the emphasis on professional leadership in the proposals as the opposite of self-directed support and wanted assurances that professional leadership would be accompanied by the robust public involvement put forward. As one focus group commented in reflection of question 11, “if people know their own care needs they should be offered SDS and services should not make assumptions about people.”

Many of the examples given in answer to question 11 on the consultation (and contained throughout this response) show why disabled people are enthusiastic about self-directed support.

In addition, in order to make successful interventions with health and social care in a truly preventative and joined up way, it is felt that other departments and budgets should be involved. For example, in order to leave hospital, sometimes people need specific adaptations in the home. This means that practitioners such as occupational therapists often need to work closely with housing officers, social care and health officials. Furthermore, some children with complex conditions will need support to access education whilst accessing the health service, it may be beneficial for health care practitioners to work closely with the local education authority in this instance. Therefore, it is suggested that integration across such areas could add value to the current proposals.

For further information on this response, please contact:

Pam Duncan, Policy Officer, Independent Living in Scotland

Suite 111, Pentagon Centre, 36-38 Washington Street, Glasgow G3 8AZ

Email – pam@ilis.co.uk Telephone – 0141 248 1943