1. **Introduction**

The Princess Royal Trust for Carers (The Trust) welcomes the opportunity to submit written information to the Health and Sport Committee as it takes forward its Integration of Health and Social Care inquiry.

We are waiting to see the detail underpinning the recent announcement about integrated health and social care services and will seek to contribute positively to the consultation, ongoing debate, legislation and process leading to the creation of Health and Social Care Partnerships.

We welcome the strong emphasis on prevention in statements to date about integration. There is increasing evidence which demonstrates the preventative outcomes of carer support for both carers and those whom they support.¹

This submission lays out why recognition of and support for carers should underpin the Scottish Government’s plans for integrated services from strategy and planning for the legislation, through to resulting guidance and arrangements at local level as Health and Social Care Partnerships are set up.

2. **Key Points/Recommendations**

In this submission, we aim to address the key areas identified by the Committee, namely:

- The challenges which exist in better integrating health and social services and exemplars of good practice

- The detail which Scottish Government’s proposals should address to overcome the barriers to integration.

In doing so, we have identified the following key points and recommendations for consideration:

- Recognition of carers and the need to directly support them should be a key principle in the legislation to create Health and Social Care Partnerships. The nationally agreed outcomes to be introduced must include a focus on unpaid carers and their own health and wellbeing and be part of the framework which will link to Single Outcome Agreements and local outcomes. This must also filter through to local arrangements and in learning from the Change Fund, we would ask that carers/local carers organisations are represented in strategic and operational governance arrangements.

¹ Supporting Carers – The Case for Change, The Princess Royal Trust for Carers, 2011
• We would ask the Committee to take account of the role and contribution of the voluntary sector and local carers’ organisations in achieving the vision for and in the delivery of integrated services. Carers’ Centres have a particular role to play in preventative support.

• We would ask the Committee in agreeing its findings to strongly emphasise the need to maintain a focus on the “human face” of integration. The actual experience of unpaid carers and their families is critical in understanding the challenges which they face in accessing personalised, integrated support and the challenges which both the Government and local partnerships will face in achieving transformational change. For example, involving carers who are currently supporting implementation of the Carers’ Strategy could be a good starting point.

• Effective and timely consultation and communication with families and carers needs to be a continuing and underpinning element of integration plans at national and local level.

• Examining local best practice across sectors particularly in relation to carer support could provide invaluable learning around the practical issues involved in creating a better experience for services users and carers and understanding the dynamics of bringing different professionals together.

• It is important to consider the role of services such as housing, Skills Development Scotland and others in achieving positive outcomes for adult service users and carers. Specific activity to look at challenges that exist with adaptations, and the role of housing in tackling isolation and supporting independent living is critical.

Previous and current work to create more integrated services highlights common themes and challenges which the Government’s plans and local partners will need to consider. These include:

• The need for political leadership and commitment to make integration happen at local level. This clearly exists at national/Government level in Scotland.

• Integration of resources – staff and finance – can lead to service improvements e.g. expansion in intermediate/community based care.

• Involving staff at all levels from the outset is critical and a clear focus on outcomes and service improvement provides a foundation for success.

• Data sharing protocols and more integrated patient/client recording systems must be a critical element in planning to better integrate services in Scotland. It is also important in developing a joined up approach at local level, where it matters most to individuals and their families.
• Clear financial systems must exist to support the delivery of integrated services

• Co-location can help joint working; creating the right environment for integration is important and this can be underpinned by the existence of a clear, shared vision for services across partners - a vision which must also be shared by service users and carers.

• The Change Fund/Reshaping Care - Evaluation of how the Change Fund is operating in localities could directly inform plans for effective integration. Evaluation of the role that the voluntary and independent sectors have as partners in Reshaping Care and the engagement of local carers' organisations at strategic level within local partnerships can also be of use in shaping the Government's plans.

• What learning can be gained in work outwith health and social care e.g. in education settings, where integrated working has produced positive outcomes?

2. The Princess Royal Trust for Carers – background

The Princess Royal Trust for Carers (The Trust) is the biggest provider of direct support to unpaid carers in the UK, working through a network of independent Carers’ Centres which place carers, young carers and their families at the heart of the services they deliver.

In Scotland, The Princess Royal Trust for Carers currently helps almost 53,000 adult carers and more than 4,300 young carers to cope with their caring role through 29 Carers’ Centres and 23 young carers’ services. The Trust also helps thousands more through interactive websites www.carers.org and www.youngcarers.net.

Carers’ Centres provide holistic, personalised and specialist carer support services which include information and advice, emotional and practical support and interventions which can directly impact on the carers' health and wellbeing and ability to continue caring. This approach takes account of the full context in which carers and their families live. Each Centre acts as a local hub which brings together partners and services to better support unpaid carers in their communities. Centres act as a gateway between hospital/institutional settings and communities, helping carers and their families understand what services are out there and in making the right choices about the support needed to help someone stay at home.

A recent evaluation carried out by Baker Tilly for The Trust highlighted the impact of carer support offered by Carers’ Centres, with a £5m investment in five Centres generating returns valued at over £70 m. ² Baker Tilly assessed that a premium is achieved by Carers’ Centres because services are provided from one locus and holistically rather than on a more piecemeal basis by

²http://www.bakertilly.co.uk/SiteCollectionDocuments/Social%20housing/Princess%20Royal%20Trust%20for%20Carers.pdf
multiple providers. If these carer support services were provided separately, the evaluation judged that the total value/return on investment would be 13% lower because of lower gains to the carer.

Our work with Carers’ Centres provides a strong understanding of the issues that affect unpaid carers and their families including their experience of health and social care services in Scotland. Centres are already working closely with statutory and independent partners in ways which bring to life the principles of integrated services and outcomes. As such, we would ask the Committee in its considerations to take account of the role and contribution of the voluntary sector and local carers’ organisations in achieving the vision for integration outlined by the Scottish Government before Christmas 2011. The drive to make integration happen provides the strongest opportunity for decades to reform key public services emphasising the importance of prevention and the specific contribution of the voluntary sector and in particular, local carers’ organisations in this context. Their direct ability to support carers means they have a critical role to play.

3. Unpaid Carers Critical to Integration

There are over 657,000 adult carers in Scotland (Scottish Household Survey, 2007/8). Replacing this care would cost over £10.3 billion annually, similar to the cost of delivering the NHS in Scotland. As significant providers of health and social care, their contribution in both shaping and achieving integration is critical.

Older people provide far more care than they receive; over two thirds of carers in Scotland are aged 50 years and over with increasing numbers balancing work and caring in their 60’s. Increasing numbers manage dual caring roles – the so-called “sandwich generation” of carers who may care for an elderly parent but who may also be caring for grandchildren, a disabled partner or sibling etc., as outlined in “Always on Call; Always Concerned”. As our population gets older, we find more older couples who provide care for each other – sometimes called ‘mutual caring’.

Without the contribution of carers, health and social care services would not cope, however these services are configured. Directly supporting unpaid carers to continue caring has a number of benefits to health and social care delivery. This is what the joint Scottish Government/CoSLA Scottish Carers’ Strategy has to say:

“With the ageing population, the number of carers is expected to grow to an estimated 1 million by 2037. ...Society as a whole will become even more dependent on the vital contribution to health and social care delivery. Carers are at the heart of the solution.”

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3 Caring in Scotland – Analysis of Existing Data Sources on Caring in Scotland, Scottish Government (2010)
4 “Always on Call; Always Concerned” The Princess Royal Trust for Carers, 2011
“Providing support to unpaid carers makes economic sense by saving resources in the longer term. With appropriate and timely support, carers are able to care for longer…unsupported; they can experience real hardship financially, physically and emotionally. It is much more likely that a cared for person will be admitted to hospital and the carer’s own health deteriorate if the carer is unsupported.”

Identification of and direct support for unpaid carers should therefore be an important element of integration plans and as such, we would argue that recognition of carers and how they are supported to care should be a key principle in the legislation to create Health and Social Care Partnerships. The nationally agreed outcomes to be introduced must include a focus on unpaid carers and their own health and wellbeing, and be part of the framework which will link to Single Outcome Agreements and local outcomes.

4. What have the challenges been in better integrating health and social services and are there exemplars of good practice?

The potential challenges which Scotland might face are mirrored at UK level and indeed in other countries. The Deputy First Minister highlighted this point in her speech to Parliament on 15th December 2011:

“There is now a consensus around the contention that separate – and all too often – disjointed systems of health and social care can no longer adequately meet the needs and expectations of people, who are living longer…and who …need joined up, integrated services”.

The experience of unpaid carers and their families is critical in understanding the challenges which they face in accessing personalised, appropriate and more integrated support. These challenges are described vividly by one carer as “the bureaucracy which surrounds caring”. This can range from dealing with social care assessments and paperwork including financial assessment; navigating through the existing infrastructure as well as co-ordination and communication issues between health and social care. Challenges also exist around:

- Post diagnostic support where carers have to deal with the consequences of a specific diagnosis and what this will mean for them and their families;

- Hospital discharge planning and direct involvement of carers in this;

- Changing eligibility criteria and increased charging which can affect whether carers and those they support can access/afford appropriate services.

- Local implementation of personalisation and self-directed support policy which can impact directly on carers and their families in terms of how support packages are or could be configured.

- Getting access to sometimes inexpensive equipment, adaptations or home care but having to wait for this. This can include, for example, having
someone work closely with a family/mediating to help achieve more speedy discharge from hospital or in ensuring there is appropriate support in place which can enable a loved one to stay at home rather than being admitted to institutional care.

In addition, research including “Sick, Tired and Caring” highlights the need for “...better, more coordinated services”\(^6\), whilst “Always on Call, Always Concerned” highlights the impact of inflexibility in existing support services for older carers \(^7\) - e.g. set ‘tuck in’ times, inability to access GP appointments which suit carers/family members particularly when caring for more than one person. These challenges create additional stress for carers of all ages impacting on their own health and wellbeing and ability to continue caring. “Always on Call...” also emphasises the need for health and social care services to work together to offer alternative care packages to tackle the issue of carers, and older carers in particular refusing treatment and appointments which deal with their own health issues. As the research points out:

“Our society depends on older carers. With an ageing population ever more people will take on a caring role in their retirement.”

The journey towards more integrated services has been in motion for a number of years already, and in Scotland, across the UK and globally, governments are seeking to deal with the challenges of increased demand for services, changing demography and tight finances in similar ways – more effective working together of services and more integrated approaches.

Integration of health and social care can happen at different levels. Some examples of existing work to bring services together are outlined below. It’s important to point out that at local level, partners can and do work together to ensure that older people and their carers are supported effectively; voluntary sector organisations such as Carers Centres have a key role to play.

4.2 Examples of Integrated Services/Approaches

4.2.1 Integration in Torbay is held up as an example of good practice and has been evaluated to show some positive results.

Torbay as an area represents a microcosm of the demographic challenges faced in the UK and Scotland. What is more, many elderly people who have retired to the area do not have family support networks nearby and are therefore more reliant on local services.

“Integrating Health and Social Care in Torbay - Improving care for Mrs Smith”\(^8\), is an evaluation of the integration process and impact for service users in Torbay. It cites the following learning points:

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\(^6\) “Sick, Tired and Caring”, Carers Scotland, 2011

\(^7\) “Always on Call, Always Concerned” – The Princess Royal Trust for Carers,

\(^8\) Integrating Health and Social Care in Torbay – Improving Care for Mrs Smith. The King’s Fund, March 2011

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- Pooling of budgets provided a wider range of care services including more intermediate and home based support.
- There were strong links between GPs and integrated teams.
- Outcomes included reduced use of hospitals, reduced rates of emergency admissions, and admissions to residential care; also an increase in home care support.
- There was an increased uptake of direct payments.

Issues highlighted in the Torbay scenario include the importance of strong leadership and commitment to making integrated services work. This included strong political commitment to change which partly arose from the need to tackle underperformance and quality issues in local social care services. Involvement of staff affected at all levels and a strong focus on achieving better outcomes for service users seem also to have been key elements in the work to integrate services.

Provisions to enable more effective sharing of data between services were also deemed to be important to success. This included named coordinators who could access patient information and data sharing agreements/actions in GP practices.

Data sharing protocols and more integrated patient/client recording systems must be a critical element in planning to better integrate services in Scotland. It is also important in developing a joined up approach at local level, where it matters most to individuals and their families. One of the biggest frustrations continually faced by carers and their families is having to “tell your story” to different professionals, sometimes on many different occasions and to people who may be co-located/work in the same team. This contributes to the disjointed experience and shunting between services which families can sometimes experience.

Other models of integrated approaches include North East Lincolnshire Care Trust Plus, where a care summit in 2010 identified key barriers to integrated service delivery in the context of tightening local finances and the beginning of GP commissioning. These included:

- The need for co-location – bring professionals together
- The need for strong leadership, in this case clinicians are mentioned
- Clear financial systems which support integrated care
- A strong focus on improving the quality of care for individuals and the wider population.

The services provided by North East Lincolnshire Care Trust Plus cover a substantial range of adult health and care services ranging from mental health to day care services, meals on wheels, complex case management and intermediate/rehabilitation services. Benefits of pooling budgets and integrated teams include:

- A reduction in formal social care referrals
- A greater focus on prevention and re-enablement driving redistribution of resources
- More people being supported to live at home
- Carer and user engagement and ‘ownership’.
- Wider ‘total care’ outcomes in commissioning

A presentation by the Care Trust Plus at a Reshaping Care event in 2011 highlighted successes relating to harmonisation of terms and conditions and integrated management and integrated team structures.\(^\text{10}\)

4.2.2 The lead agency model in Highland is cited in the briefing provided by Committee officials

A dedicated website provides information on work done to date:

http://highlandlife.net/planning_for_integration/about_the_project

The Highland model is wider than health and social care as it includes education/children’s and leisure/cultural services, although a recent council paper highlights that in the latter case, integrated budgets will not be in place immediately.\(^\text{11}\)

Recent NHS Board/Council Papers outline progress to date with a Commission being developed to ensure safe transfer of power. This will be based on learning from other similar partnerships across the UK and will include a partnership agreement, strategic outcomes, performance management and delivery specifications and commissioning. The importance of working with staff across different services before, during and after the transition also features strongly.

What is striking about some of the information provided in these papers is the complexity involved in disaggregating and restructuring services, and the apparent complexity in the proposed new governance/partnership structures.\(^\text{12}\) A clear point of access and contact for service users and carers is clearly

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\(^{10}\) http://www.jitscotland.org.uk/action-areas/reshaping-care-for-older-people/change-fund-event-2-february-2011/

\(^{11}\) “Planning for Integration of Services for Adults and Children” Chief Executive’s report to Highland Council, Dec 2011.

\(^{12}\) Section 6 – “Planning for Integration of Services for Children and Adults” – Highland Council December 2011.
important – and that may not always be through statutory services. The critical role of unpaid carers and the need to effectively support them does not seem to be fully reflected in these new structures.

There are strong plans around engagement of service users but carers and their families understandably feel concerned about the services they currently receive. This will apply nationally to the Government’s plans to integrate adult health and social care services. It is important to point out that in developing real opportunities for consultation, not all carers and service users will be able to attend formal engagement events or keep in touch with developments online as services plan to become more integrated. This highlights the need for continual reinforcement of key messages using a range of media, but also the need to continue working with local community based organisations which directly support service users and their families. **Consultation and communication with families and carers to be a continuing and underpinning element of integration plans at national and local level.**

The role of voluntary organisations and their contribution and expertise in working with those affected by plans in local communities is important but their contribution to shaping national plans and outcomes is equally critical.

### 4.2.3 Change Fund

The Change Fund linked to Reshaping Care for Older People effectively ‘pump primes’ closer working across health, social care and other partners. Investment in the Change Fund could be seen to ‘pave the way’ for more integrated services and a shift of resources ‘upstream’ towards preventative, community based services.

Evaluation of how the Change Fund is operating in localities could directly inform plans for effective integration. The recognition of the need to directly and indirectly support unpaid carers, as key contributors to health and social care within the Change Fund is an important step and must be mirrored in plans, legislation and outcomes for integrated services at both national and local level.

Evaluation of the role that the voluntary and independent sectors have as partners in Reshaping Care and the engagement of local carers’ organisations/Carers’ Centres at strategic level within local partnerships can also be of use in shaping the Government’s plans. Issues relating to parity of esteem for the third sector in year 1 of the Change Fund must be effectively addressed. There is scope for local Change Plans to evolve and support local plans for integration. It is important to highlight that in some local areas, the importance of supporting carers is reflected in the direct involvement of local carers’ organisations in planning for reshaped services/Change Fund spend - e.g. Dundee, West Lothian and West Dunbartonshire.

### 4.2.4 Integrated Activity at Local Level

Much can be learned from local examples of integrated service delivery and joint working across all sectors, including the voluntary sector. Primed by
investments from local authorities, Carer Information Strategy funding and the Change Fund, these activities involve health, social care and voluntary sector workers combining their skills and expertise to deliver better services for carers and their families.

Carers of West Lothian is co-located in the local ‘partnership building’ and frontline council and health care staff refer carers directly for support. Other examples of integrated approaches include:

- At a strategic level, the organisation is represented on the sub-committee of the CHCP which reports directly to the CHCP board.

- In Templar Day Hospital, a Carer Support Worker from Carers of West Lothian is part of multidisciplinary team meetings which include identification of and support for unpaid carers.

- Since 2004 training and a drop in group for carers of people who are in the early stages of dementia has been carried out jointly by Carer Support staff working with hospital staff at St. John’s.

- Delivery of Wellness and Recovery Action Plan (WRAP) training jointly with the CHCP health improvement team for carers.

- Joint work with statutory services around falls management which includes training around moving and handling and aids/adaptations.

  Joint working with West Lothian Council and other voluntary sector partners to set up a sibling support group for young carers.

- Regular liaison meetings with senior social workers and Carer Support Workers around information sharing.

In other areas, links with GP practices, Acute Hospitals, joint training and representation on CHPs/CHCPs lead to more integrated services and approaches directly involving the expertise of Carers’ Centres and therefore carers themselves. Delivery of training to unpaid carers involving local authorities and voluntary sector carers’ organisations is being funded by the Scottish Government as part of its drive to implement the Self Directed Support Strategy.

4.2.5 Joint Future

The Joint Future work in the early years of the Scottish Parliament has been acknowledged e.g. in the recent integration debate in the Scottish Parliament. The very issues and challenges that it, and provisions within the Health and Community Care Act 2002 were set up to deal with, are those which the current Government may also seek to address through its plans and through legislation. These include pooled budgets, delegation of responsibility for services, joint management of staff, resources, property etc.
Work to “reinvigorate Joint Future” highlighted the need to focus on clear outcomes for service users and carers as a key element of local partnership working across services. It is encouraging that identification of key outcomes for integrated services has been the starting point of this next stage of the integration journey in Scotland.

Lessons around joint premises development within Joint Future have wider application for integration of services. These included the need to ‘pump prime’ developments and the experience and readiness of staff for joint working. In addition, there needs to be, as outlined in the Torbay scenario, a suitable environment for joint working, supported by strong political commitment. An agreed, shared vision across partners is also important.

4.2.6 Other Examples outwith Health and Social Care

It may be worth looking back at other examples of integrated approaches, some of which involved co-location of different professionals e.g. in education settings. These include Community Schools where the actual physical integration of teams in some schools helped focus on joint working and effective support for identified pupils. Joint group work and activities with pupils was a key element of such work.

The Enhanced Resources Pilot – funded by the Scottish Executive - brought Careers Advisers into schools at early stages to work directly with school teams to support young people at risk of not making a positive transition – becoming part of the school team was key to success in identifying an action plan to tackle poor post school destinations.

The GIRFEC approach has helped bring together a range of professionals, including those from third sector organisations and is the delivery mechanism for improving outcomes for children and young people. As an integral part of Community Planning Partnerships, it has helped drive closer working between services and not just those within health and social care.

How the new Health and Social Care Partnerships sit in relation to Community Planning Partnerships must be considered. A strong link between Single Outcome Agreements and the integration agenda will be important in driving forward the transformation envisaged by the Scottish Government. The role of services such as housing, Skills Development Scotland and others in achieving positive outcomes for adult service users and carers should also be considered. Linking to ongoing work with looks at challenges around housing and adaptations is important – the role of housing in tackling isolation and supporting independent living is critical.

5. Conclusions

The commitment to achieve transformation of services through integration affords us all an immensely positive opportunity. We must look beyond this

13 Joint Future Agenda: Short Life Working Group on Premises Development in Primary and Community Care, 2003
though to the ‘human element’ and the experience of individuals and unpaid carers in how services currently work and in what integrated services might look like. Direct carer involvement e.g. perhaps through the Carers Strategy Implementation Group would be a possible way of achieving this.

Our focus on integrating services must always remain focussed on what individuals and unpaid carers tell us. This was highlighted succinctly by inputs from MSPs across all political parties during the debate on integration in the Scottish Parliament.

We look forward to working closely with all key partners to shaping the journey ahead.

The Princess Royal Trust for Carers