Corporate Policy and Strategy Committee

10am, Tuesday, 13 May 2014

Edinburgh Joint Carers' Strategy and Joint Strategic Commissioning Plan for carer support

Item number 7.7

Report number

Executive/routine Executive

Wards All

Executive summary

The purpose of this report is to outline the feedback from the consultation on the draft Edinburgh Joint Carers' Strategy. The report also seeks approval of the Edinburgh Joint Carers' Strategy and the priorities for carer support as well as the associated Edinburgh Joint Strategic Commissioning Plan for carer support.

Edinburgh's Joint Carers' Strategy has been developed in collaboration with key local stakeholders from Health, Local Authority, the voluntary sector and carers. The strategy outlines local priorities and outcomes for carers in Edinburgh for the next three years from 2014 to 2017. There are six priority areas identified within the strategy:

- identifying carers
- information and advice
- carer health and wellbeing
- short breaks / respite
- young adult carers
- personalising support for carers.

Links

Coalition pledges P39
Council outcomes C012
Single Outcome Agreement S02

Report

Edinburgh Joint Carers' Strategy and Joint Strategic Commissioning Plan for carer support

Recommendations

- 1.1 It is recommended that Corporate Policy and Strategy Committee:
 - Notes the feedback from consultation on the draft Edinburgh Joint Carers' Strategy
 - 2. Considers and approves the Edinburgh Joint Carers' Strategy
 - 3. Considers and approves the Edinburgh Joint Strategic Commissioning Plan for carer support
 - 4. Notes that due to the level of overall funding of the procurement exercise, the Finance and Resources Committee will be asked to approve the award of specific contracts in due course.

Background

- 2.1 The provision of support to unpaid carers is a key local and national priority. There are over 492,000 unpaid carers in Scotland (Census 2011). This is almost one in ten of the Scottish population who are involved in providing care and support to a family member, friend or neighbour to enable that person to continue to live in their own community. However, caring for someone can often continue even when the person leaves their own home and moves into a care home or other residential setting.
- 2.2 The Census in 2011 revealed that the number of unpaid carers in Edinburgh dropped slightly from 38,876 in 2001 to 37,859 in 2011. In population terms, the number of unpaid carers in 2001 represented 8.7% of the total population in Edinburgh and this reduced to 7.9% in 2011.
- 2.3 However, the proportion of carers who provided 20 or more hours per week of unpaid care rose from 30.6% in 2011 to 36.2% in 2011. This equates to an additional 1,826 unpaid carers in the city undertaking unpaid care for more than 20 hours per week in 2011 as compared to 2001. In addition, the proportion of carers who provide 50 or more hours per week of unpaid care also rose slightly from 20.3% in 2001 to 21.1% in 2011. In terms of numbers, 8,004 unpaid carers

provide 50 or more hours per week of unpaid care, which is 21% of all unpaid carers in Edinburgh.

- 2.4 A draft Joint Carers Strategy was developed in 2013 in partnership with a multi-agency working group. City wide and local consultation was undertaken from 02 September to 31 October 2013 on the draft Joint Carers' Strategy using a collaborative approach. An online and printed questionnaire was used to gain feedback from the public and stakeholders. There were a series of focus groups held by carer organisations including VOCAL, MECOPP, Edinburgh Young Carers Project and Care for Carers. This aided feedback and encouraged carers to raise issues and complete questionnaires in their own right. The analysis of the consultation demonstrated strong support for each of the six priorities. This analysis is available on the Council website, here.
- 2.5 In order to implement the Edinburgh Joint Carer's Strategy, a Joint Strategic Commissioning Plan for carer support in Edinburgh has been developed (see appendix 1 Edinburgh Joint Strategic Commissioning Plan for carer support). As there are a number of carer support block contracts that ended in March 2014, there is a requirement to take these to a procurement exercise to obtain best value and alignment to the six key priorities in the strategy.

Main report

Feedback from consultation on the draft Edinburgh Joint Carers' Strategy

- 3.1 The consultation was widely promoted through the city using a collaborative approach from 02 September to 31 October 2013. The main respondents were carers (92%). The age range of respondents was from those under 12 years of age to those over 75 years. There were 18 responses from support providers and organisations including NHS Lothian, NHS Education for Scotland, Edinburgh Young Carers Project, Queensferry Care, Children 1st, Carr Gomm, Caire, West Lothian Young Carers Project, LifeCare, Circle and Care for Carers.
- 3.2 There were also eight reports from several carer organisations and feedback from other forums or meetings, including MECOPP, VOCAL, Edinburgh Young Carers Project, Edinburgh Carer Network, Edinburgh Children's Partnership, Deputy Head Teachers meeting and the Lothian Chambers Consultation Event on 09 October 2013.
- 3.3 In terms of demographics, 12% of respondents were young carers under 16 years old, only 2% were aged 16 to 25, 40% were aged 25 to 64 years old and 43% were 65 years and older. Of those respondents aged over 65 years old, 17% were aged 75 and over.
- 3.4 A series of internal and external meetings to deliver presentations on the draft Joint Carers' Strategy by Council officers helped to promote the consultation and raise awareness of the priorities. This approach allowed for many individuals to be

- consulted on the strategy. Presentations on the strategy consultation included those at the Carers Scotland Forum in St John's Church and a stakeholder event at Lothian Chambers.
- 3.5 Carers' organisations used their newsletters to get the message of the consultation out through their networks. VOCAL informed over 5,000 carers of the consultation and the link to consultation papers, via a dedicated flyer and household mailing. They followed this up in two e-bulletins in September and October to 1,500 plus carers.
- 3.6 VOCAL held nine carer focus groups in September and October 2013 in which a total of 46 carers attended. MECOPP held two focus groups, one for South Asian carers and one for Chinese carers, in which a total of 32 ethnic minority carers attended. Care for Carers sent out information on the consultation via their networks to 900 carers via a newsletter and held a focus group, which thirteen carers attended.
- 3.7 A letter was sent out to over 600 carers who had been assessed by the Council in the last year along with those who were in receipt of the carer's emergency card. The letter invited these carers to respond to the consultation and included a questionnaire and a freepost return envelope. In addition, an electronic flier was used to circulate awareness of the consultation to all Health and Social Care staff, NHS Lothian staff, GP practices, Neighbourhood Partnerships and the Edinburgh Carer Network.
- 3.8 The analysis of the consultation demonstrated strong support for each of the six priorities. It also outlined some additional gaps and suggestions for service improvements as seen by respondents who were mainly unpaid carers (92%). These included the following:
 - Drop in's for carers at GP surgeries
 - More district nurses who would visit elderly and disabled people in their homes
 - More flexible short breaks, tailored to individual needs and more breaks
 - More information on short breaks
 - More dedicated young adult carer support (aged 16 to 25)
 - Improve transition services between young carer and young adult carer support
 - Continue to provide support to young carers through schools, colleges, community centres and GP surgeries
 - More and better financial and benefits advice and help for carers
 - More emotional support, information and advice
 - Contact numbers for help in the house and reliable tradesmen
 - More funding for support groups
 - Consider the needs of people from other Ethnic groups other than White British /European
 - DVD's and information packs to distribute information including social hubs, libraries and GP surgeries
 - Establish a carers register

This feedback along with the results established from the mapping exercise of carer support undertaken in 2013 was taken into consideration in the revised Joint Carers' Strategy. This will be taken forward in the ongoing discussions with Council departments and NHS Lothian and addressed through the implementation of the pending action plan. This analysis and the mapping report are available on the Council website, here.

Edinburgh Joint Carers' Strategy

- 3.9 The Edinburgh Joint Carers' Strategy has been developed in collaboration with key local stakeholders from Health, Local Authority, the voluntary sector and carers. The strategy outlines local priorities and outcomes for carers in Edinburgh for the next three years from 2014 to 2017. The City of Edinburgh Council and NHS Lothian recognise the vital role that carers contribute to their communities across Edinburgh. A range of good quality support needs to be available to carers at the right time and place. This is to ensure that the individual needs of carers are met. With the advent of self directed support, there will be more opportunities to have more personalised support which will empower them through improved choice and control (see appendix 2- Edinburgh Joint Carers' Strategy).
- 3.10 Our vision for adult carers in Edinburgh is that, "that they are able to live healthy, fulfilling lives and that they will be valued as equal partners in the provision of care and inform decisions about carer support. Carers will be able to sustain their caring role, if appropriate and if they choose it." For young carers, our vision is, "we want to ensure that young carers are enabled to be children and young people first and foremost and relieved of any inappropriate caring roles to allow them to have a quality of life."
- 3.11 The intention is that the strategy will be the main roadmap for carer support and improved outcomes to both young carers and adult carers. The six priorities are broad strategic areas in relation to support for carers. Each has related sub categories as below:

Priority	Sub-Categories
Identifying carers	Awareness raising and publicity, hard to reach groups, workforce training of carers needs and issues, working with employers / education providers, carers assessments, carer self-identification
Information and advice	Carer training, financial planning support, welfare benefits advice, carer advocacy, online and printed information and advice

Carer health and wellbeing	Flexible carer support, one to one support, group work, emotional support, counselling, emergency planning
Short breaks / respite	Flexible and creative short breaks
Young adult carers	Transition, identification, support, employment, training
Personalising support for carers	Meeting individual needs, Self directed support, choice and control, GIRFEC

3.12 Through the implementation of the Joint Carers' Strategy these six priorities will be addressed by undertaking a range of activities to support carers across the city. The impact will be measured through a range of identified outcomes which will be met from the various activities from all stakeholders and agencies in the form of identifying carers, referral, assessment and support. Therefore, the outcomes set out the expected impact of what's happening in terms of carer support provided by all agencies across the city. By measuring outcomes, this ensures that information is collected on whether support provided for the carer makes a positive impact on their lives.

Edinburgh Joint Strategic Commissioning Plan for carer support

- 3.13 The Edinburgh Joint Strategic Commissioning Plan for Carer Support (The Plan) should be read in conjunction with the Commissioning Plan for Adult Social Care (2011-2016). The Plan has been developed alongside the Edinburgh Joint Carers' Strategy (2014-2017).
- 3.14 The Plan has been developed following an engagement and consultation process on the draft Joint Carers' Strategy with stakeholders, carer organisations, carer projects and carers themselves. It has also taken onboard findings from the review of the previous joint carers' strategic action plan, *Towards 2012* as well as the recent mapping exercise of carer support in 2013.
- 3.15 The current provision of carer support in the Council is within mainly two departments, Health and Social Care and Children and Families. In Health and Social Care, the main allocation for commissioned carer support is £882K, which is made up of block contracts and grants. However, Health and Social Care also provides statutory assessment and care management services to carers as well as statutory and commissioned respite and short breaks services (See table A over).

Funding Organisation	Funding Department	Funding Source	Amount of funding (£) 2013/14
The City of Edinburgh Council	Health and Social Care, Children and Families	Carers Support Payment, VolunteerNet, Carer Emergency Card	500,000
	Health and Social Care	Carer support contracts	628,745
	Health and Social Care	Carer support grants	253,824
	Health and Social Care	Change Fund- Carer Support Hospital Discharge service	100,000
	Health and Social Care	Change Fund* Innovation Fund	60,692
	Children and Families	Young carers support grants	75,752
NHS Lothian	NHS Lothian Board	Carer support contracts	76,386
	Edinburgh CHP	Carer Information Strategy funding	408,677
		Total	2,104,076

Table A: Funding sources for carer support in Edinburgh 2013/14 (*This table includes Change Fund projects for carers only. Other Change Fund projects not listed also provide direct and indirect support for carers).

3.16 There are currently seven carer organisations and carer projects whose contracts ended in March 2014. These are as follows: VOCAL, MECOPP, Crossroads Caring Scotland (Edinburgh), BEMAS, Caire project, Health in Mind (respite service) and Queensferry Churches Carer Support. There is a requirement to take these to a procurement exercise to obtain best value and alignment to the six key priorities as identified through the Edinburgh Joint Carers' Strategy. The Council has a duty to seek best value and in line with the Commissioning Plan for Adult Social Care (2011-2016).

- 3.17 A report will be submitted to the Integrated Management Team in May recommending an extension to those carer support contracts we currently have with a number of organisations which ended on 31 March 2014. If the recommendation is approved, these contracts will be extended to October 2014 by issuing shorter temporary contract extensions. This will ensure there is no interruption to the funding of currently contracted organisations and allow for a procurement exercise to be undertaken.
- 3.18 All grants for carer support services will not be part of this procurement exercise as they have been already been approved for 2014/15. If a future opportunity arises to review this situation, then alignment of carer support services to the six priorities will be a paramount driver.
- 3.19 Carer Information Strategy (CIS) funding will not be part of the procurement exercise as this funding is time limited and is only guaranteed for another two years, 2014/15 and 2015/16 by the Scottish Government.
- 3.20 Although the overall value of the carer support contracts is £628,745 per annum, it is proposed that not all of this funding will be externally commissioned. A proportion, £46,963 allocated to MECOPP's care at home service will be transferred across to Adult social work sector services as part of their overall care at home budget. This will improve the process of access to this service.
- 3.21 Another proportion, £36,000 will be set aside by the Council, to fund an external pilot for alternative approaches to carer assessment; carer involvement in planning of services; carer awareness raising and publicity including carer events, design and printing of carer information. These allocations are as follows:

Priority	Service outline	Nominal allocations (£) per annum
Identifying carers	Carer assessments pilot (1 year pilot with possible extension dependant on evaluation)	20,000
Personalising support for carers	Carer involvement in planning; expenses/ replacement care	6,000
Identifying carers/ Information and advice	Carer awareness raising and publicity including carer events, design and printing of carer information	10,000
	Total	36,000

Table B: Proportion of funding set aside by the Council to fund carer support

3.22 The overall funding for the procurement exercise is £622,168 which includes the Council's proportion from carer support contracts and the funding that NHS Lothian has agreed to resource transfer for this purpose, £76,386. The table below outlines the nominal allocations for the procurement exercise of carer support contracts against each of the six priorities:

Priority	Sub-categories	Service Outline	Nominal allocations (£) per annum
Identifying carers	Awareness raising and publicity, hard to reach groups, workforce training of carers' needs and	1.Carer awareness raising; working with employers/ education providers	40,000
	issues, working with employers / education providers, carers assessments, carer self-identification	2.Carer identification and support to 'hard to reach' groups including BME groups/gypsy travellers/ LGBT carers etc	30,000
Information and advice	Carer training, financial planning support, welfare	1.Carer Training, specific to caring situation or condition	30,000
	benefits advice, carer advocacy, online and printed	2.Carer Training, learning opportunities	30,000
	information and advice	3.Financial planning/welfare benefits advice support to carers	30,000
Carer health and wellbeing	Flexible carer support, one to one support, group work, emotional support, counselling, emergency planning	Carer health and wellbeing support service in South West Edinburgh. Offering practical and emotional support//group work/ one to one support to carers	30,000
Short breaks / respite	Flexible and creative short breaks	Flexible short breaks (respite) /sitter services for adult carers in all care situations	292,168
Young adult carers	Transition, identification, support, employment, training	Support for identifying, transitions and support to young adult carers	50,000

Personalising support for carers	Meeting individual needs, self-directed support, choice and control, GIRFEC framework	Carer support workers (x3) Providing personalised support services and meeting individual needs of carers.	90,000
		One worker based in South West Edinburgh, one based in South East Edinburgh and one based in North West Edinburgh	
		Total	622,168

Table C: Nominal allocations for procurement exercise for carer support.

- 3.23 The nominal amounts of funding against each priority are varying amounts to take into account other funding of services in these areas from other funding sources such as CIS funding or carer support grants. Also, feedback from consultation, the mapping exercise and other strategic information helped to shape these allocations against each priority area. Overall, the Plan is in line with the Edinburgh Joint Carers' Strategy.
- 3.24 Following on from the outcome of the procurement exercise, we will have established a suite of new contracts with commissioned providers to deliver on the six priorities within the Edinburgh Joint Carers' Strategy. These will be outcomes based contracts and aligned to the fourteen outcomes identified in the strategy.

Measures of success

4.1 The measures of success will be evidenced through regular monitoring, evaluation and reporting of the implementation of the Edinburgh Joint Carers' Strategy via an action plan.

Financial impact

5.1 Funding for carer support in Edinburgh comes from the City of Edinburgh Council and NHS Lothian. The third sector also brings considerable investment to the city.

Risk, policy, compliance and governance impact

6.1 The associated risks to implementing the Edinburgh Joint Carers' Strategy and the associated Joint Strategic Commissioning Plan for carer support will be

monitored both through the Strategic Planning Group for Carers and through the integrated management team in Health and Social Care. In Children and Families, the governance and progress on the action plan will be reported to the relevant Children's Partnership Strategic Oversight Group.

Equalities impact

7.1 There are no negative equality and rights impacts arising from this report. A full equalities and rights impact assessment has been completed for the Edinburgh Joint Carers' Strategy.

Sustainability impact

8.1 There are no sustainability implications arising from this report.

Consultation and engagement

- 9.1 Wide-ranging consultation was undertaken on the draft Edinburgh Joint Carers' Strategy. The consultation period was from 2 September to 31 October 2013 and was actively promoted through the city using a collaborative approach. The analysis of the consultation demonstrated strong support for each of the six priorities.
- 9.2 An online and printed questionnaire was used to gain feedback from the public and stakeholders. There were a total of 570 people consulted on the strategy and this included 317 completed questionnaires and 253 individuals who attended forums or meetings.

Background reading / external references

There are various key reports including the following:

- (1) <u>Policy, Development and Review Sub Committee of the Health Social Care and Housing Committee, 28 January 2014</u>
- (2) Towards 2012, Joint Carers' Strategic Action Plan for Edinburgh (2007-2012)
- (3) NHS Lothian Carer Information Strategy (2008-2011)
- (4) Caring Together, National Carers' Strategy for Scotland (2010-2015)
- (5) <u>Getting it Right for Young Carers, The Young Carers Strategy for Scotland (2010 2015)</u>

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Links

Coalition pledges	P39 Establish a Care Champion to represent carers
Council outcomes	CO12 Edinburgh's carers are supported
Single Outcome Agreement	SO2 Edinburgh's citizens experience improved health and wellbeing, with reduced inequalities in health
Appendices	 Edinburgh Joint Carers' Strategy Edinburgh Joint Strategic Commissioning Plan for carer support

Edinburgh Joint Strategic Commissioning Plan for Carer Support (2014-2017)

v2.0

1. Background

- 1.1 The Edinburgh Joint Strategic Commissioning Plan for Carer Support (The Plan) should be read in conjunction with the Commissioning Plan for Adult Social Care (2011-2016). The Plan has been developed alongside the Edinburgh Joint Carers' Strategy (2014-2017).
- 1.2 Edinburgh's Joint Carers' Strategy has been developed in partnership with key local stakeholders from Health, Local Authority, the voluntary sector and carers. The strategy outlines local priorities and outcomes for carers in Edinburgh for the next three years from 2014 to 2017. This integrated approach has outcomes for carers at its centre and made use of the Wisconsin Logic Model to develop the strategy. The aim is that this strategy will be the main roadmap for support and improved outcomes to both young and adult carers in Edinburgh.
- 1.3 The Plan has been developed following an engagement and consultation process on the draft Joint Carers' Strategy with stakeholders, carer organisations, carer projects and carers themselves. It has also taken onboard findings from the review of the previous joint carers' strategic action plan, *Towards 2012* as well as the recent mapping exercise of carer support in 2013.
- 1.4 The extensive consultation exercise undertaken for the draft Joint Carers' Strategy with 317 completed responses, which 92% were from carers established strong support for each of the six priority areas identified within the strategy for Edinburgh's carers which are:
- identifying carers
- information and advice
- carer health and wellbeing
- short breaks / respite
- young adult carers
- personalising support for carers.
- 1.5 A Communication and Engagement Plan was developed to ensure that the Strategy was available for wide consultation during 02 September to 31 October 2013.
- 1.6 Throughout the development of the Joint Carers' Strategy, the needs of both adult carers and young carers have been considered to ensure that the strategy and the Plan does not create or perpetuate discriminatory practice and meets the legislative requirements of the Equalities Act (Scotland) 2010. A full Equalities Impact and Rights Assessment has been completed.

- 1.7 Commissioning is the process of planning and delivering services. This involves understanding needs, planning how these should be met and putting services in place, either by delivering services directly or purchasing them. The term 'Joint Strategic Commissioning' is defined in Scotland as "the term used for all activities involved in assessing and forecasting needs, linking investment to agreed desired outcomes, considering options, planning the nature, range and quality of future services and working in partnership to put these in place" (Joint Improvement Team, 2014).
- 1.8 The four stages of the commissioning cycle includes the "Review" stage, which has already occurred as we undertook a review of the previous carers' strategic action plan, *Towards 2012* last year. The results from that review along with consultation on the draft Joint Carers' Strategy helped to shape the current Joint Carers' Strategy and Plan.
- 1.9 The "Analyse" stage is where all partners consider all the information available from consultations, census information, assessing and forecasting needs, agreeing desired outcomes, range and quality of future services and work in partnership for a vision. This has been undertaken for carer support.
- 1.10 The "Planning" stage of the commissioning process involves working with stakeholders to develop a strategy of how services need to be shaped in the future. This stage also involves developing detailed service specifications and a procurement plan. This is where we are currently. The "Do" stage is where we will be moving to next and at this stage, involves implementation of the new strategy and joint commissioning plan for carer support.

2 Current context of carer support provision

2.1 The current provision of carer support in the Council is within mainly two departments, Health and Social Care and Children and Families. In Health and Social Care, the main allocation for commissioned carer support is £882K, which is made up of block contracts and grants. However, Health and Social Care also provide statutory assessment and care management services to carers as well as statutory and commissioned respite and short breaks services (See table A below).

Funding organisation	Funding department	Funding source	Amount of funding (£) 2013/14
The City of Edinburgh Council	Health and Social Care, Children and Families	One-off funding	500,000
	Health and Social Care	Carer support contracts	628,745
	Health and Social Care	Carer support grants	253,824
	Health and Social Care	Change Fund-Carer Support Hospital Discharge service	100,000
	Health and Social Care	Change Fund* Innovation Fund	60,692
	Children and Families	Young carers support grants	75,752
NHS Lothian	Lothian NHS Board	Carer support contracts	76,386
	Edinburgh Community Health Partnership	Carer Information Strategy (CIS) funding	408,677
		Total	2,104,076

Table A: Funding sources for carer support in Edinburgh 2013/14 (* This table includes Change Fund projects for carers only. Other Change Fund projects not listed also provide direct and indirect support for carers).

- 2.2 Children and Families allocated £75,752 in year 2013/14 for support to young carers through contracts with specialist providers. The department invests in a range of other services through grants and contracts that whilst not specific young carer services, do support young carers. These include services for children affected by paternal substance use.
- 2.3 In addition, specific funding has been allocated to carer support from the Change Fund including £100,000 per annum for 2013/14 and 2014/15 for the carer support hospital discharge service in Edinburgh. Other funding for carer support in Edinburgh from the Change Fund Innovation Fund amounted to £60,692 in 2013/14. As outlined in the above table, funding includes Change Fund projects for carers only. Other Change Fund projects not listed also provide direct and indirect support for carers.
- 2.4 Lothian NHS Board via Edinburgh Community Health Partnership allocated £408K in 2013/14 to spend on carer support through the Carer Information Strategy (CIS) monies. This provides or enhances a range of service provision to both adult and young carers in Edinburgh. This national funding source, CIS funding for 2014/15 will be £5m for Scotland calculated using the NRAC

- formula. Subject to Parliamentary approval, there will be further CIS funding in 2015/2016 of £5 million. Lothian NHS Board will allocate proportionate CIS funding to each of the community health partnerships including Edinburgh.
- 2.5 In addition, Lothian NHS Board contribute to two joint contracts for carer support in Edinburgh. This amounts to £76,386 for year 2013/14. This mainly currently funds carer advocacy and carer support. A decision has been taken to resource transfer this funding to the Council as part of the procurement exercise which will be undertaken later this year.
- 2.6 One-off additional funding for carer support has been provided recently by the Council. In 2012/13, £400K was provided and this increased to £500K in 2013/14. This allowed the development of the carer's support payment, VolunteerNet and the carer's emergency card. The increase in funding in 2013/14 also helped to provide an innovation fund of £100K for kick starting new ideas or innovative small projects for carer support. A separate report on this recurring funding for 2014/15 will be provided to Committee at a future date.

3 The process of new contracts for carer support

- 3.1 As there are a number of carer support block contracts that came to an end in March 2014, there is a requirement to take these to a procurement exercise to obtain best value and alignment to the six key priorities as identified through the Edinburgh Joint Carers' Strategy. The Council has a duty to seek best value and in line with the Commissioning Plan for Adult Social Care (2011-2016).
- 3.2 There are currently seven carer organisations and carer projects whose contracts ended in March 2014. These are as follows: VOCAL; MECOPP; Crossroads Caring Scotland (Edinburgh); BEMAS; Caire project; Health in Mind (respite service) and Queensferry Churches Carer Support. There is a requirement to take these to a procurement exercise to obtain best value and alignment to the six key priorities as identified through the Edinburgh Joint Carers' Strategy. The Council has a duty to seek best value and in line with the Commissioning Plan for Adult Social Care (2011-2016).
- 3.3 A report will be submitted to the Integrated Management Team in May recommending an extension to those carer support contracts we currently have with a number of organisations which ended on 31 March 2014. If the recommendation is approved, these contracts will be extended to October 2014 by issuing shorter temporary contract extensions. This will ensure there is no interruption to the funding of currently contracted organisations and allow for a procurement exercise to be undertaken.

- 3.4 In order to meet our duty to ensure transparency and equality of opportunity in the letting of contracts, we will seek to gauge levels of interest in the contracts we want to let through the publication of a Prior Information Notice (PIN) on the Public Contracts Scotland Website, before finalising our procurement proposals. The Council will keep providers informed of the timetable for publication of the PIN, which is likely to be sometime in May/June of this year.
- 3.5 All grants for carer support services will not be part of this procurement exercise as they have been already been approved for 2014/15. If a future opportunity arises to review this situation, then alignment of carer support services to the six priorities will be a paramount driver.
- 3.6 Carer Information Strategy (CIS) funding will not be part of the procurement exercise as this funding is time limited and is only guaranteed for another two years, 2014/15 and 2015/16 by the Scottish Government.

4 Procurement Exercise

- 4.1 Although the overall value of the carer support contracts is £628,745 per annum, it is proposed that not all of this funding will be externally commissioned. A proportion, £46,963 currently allocated to MECOPP's care at home service will be transferred across to Adult social work sector services as part of their overall care at home budget. This will improve the process of access to this service.
- 4.2 The funding from NHS Lothian which has been agreed to be resource transferred to the Council is £76,386 per annum. This funding to the Council will be included as part of the procurement exercise which will be undertaken this year, aligned to the six priorities.
- 4.3 Another proportion, £36,000 will be retained by the Council, to fund a pilot for alternative approaches to carer assessment; carer involvement in planning of services; carer awareness raising and publicity including carer events, design and printing of carer information. These allocations are as follows:

Priority	Service outline	Nominal allocations (£) per annum
Identifying carers	Carer assessments pilot (1 year pilot with possible extension dependant on evaluation)	20,000
Personalising support for carers	Carer involvement in planning; expenses/replacement care	6,000
Identifying carers/ Information and advice	Carer awareness raising and publicity including carer events, design and printing of carer information	10,000
	Total	36,000

Table B: Proportion of funding retained by the Council to fund carer support

4.4 The overall funding for the procurement exercise is £622,168 which includes the Council proportion from carer support contracts and the funding that NHS Lothian has agreed to resource transfer for this purpose. The table below outlines the nominal allocations for the procurement exercise of carer support contracts against each of the six priorities:

Priority	Sub-categories	Service Outline	Nominal allocations (£) per annum
Identifying carers	Awareness raising and publicity, hard to reach groups, workforce training of	1.Carer awareness raising; working with employers/ education providers	40,000
	carers' needs and issues, working with employers /	2.Carer identification and support to 'hard to reach'	
	education providers, carers assessments, carer self-identification	groups including BME groups/gypsy travellers/ LGBT carers etc	30,000
Information and advice	Carer training, financial planning support, welfare benefits advice,	1.Carer Training, specific to caring situation or condition	30,000
	carer advocacy, online and printed information and	2.Carer Training, learning opportunities	30,000
	advice	3.Financial planning/welfare benefits advice support to carers	30,000
Carer health and wellbeing	Flexible carer support, one to one support, group work, emotional support, counselling, emergency planning	Carer health and wellbeing support service in South West Edinburgh. Offering practical and emotional support//group work/ one to one support to carers	30,000
Short breaks / respite	Flexible and creative short breaks	Flexible short breaks (respite) /sitter services for adult carers in all care situations	292,168
Young adult carers	Transition, identification, support, employment, training	Support for identifying, transitions and support to young adult carers	50,000

Personalising support for carers	Meeting individual needs, self-directed support, choice and control, GIRFEC framework	Carer support workers (x3) providing personalised support services and meeting individual needs of carers. One based in South West Edinburgh, one based in South East Edinburgh and one based in North West Edinburgh	90,000
		Total	622,168

Table C: Nominal allocations for procurement exercise for carer support.

- 4.5 The nominal amounts of funding against each priority are varying amounts to take into account other funding of services in these areas from other funding sources such as CIS funding or carer support grants. Also, feedback from consultation, the mapping exercise and other strategic information helped to shape these allocations against each priority area. Overall, the Plan is in line with the Edinburgh Joint Carers' Strategy.
- 4.6 At this stage, we are in the process of establishing a procurement timetable, which will guide the procurement exercise including putting the Prior Information Notice on the Public Contracts Scotland Website, before finalising our procurement proposals. The Council will keep providers informed of the timetable for publication of the PIN, which is likely to be sometime in May/June of this year.
- 4.7 It is envisaged that the contracts issued for these priorities following the procurement exercise will be three year contracts with possible one year extensions dependant on satisfactory performance. A final decision on this aspect will follow from award of contracts recommendations around October 2014.
- 4.8 Following on from the outcome of the procurement exercise, we will have established a suite of new commissioned contracts for carer support with providers to deliver on the six priorities within the Edinburgh Joint Carers' Strategy. These will be outcomes based contracts and aligned to the fourteen outcomes identified in the strategy.

Edinburgh Joint Carers' Strategy (2014-2017)

V1.9

Contents

Foreword by the Carers Champion, Councillor Work	3
Our vision for carers in Edinburgh	4
Introduction	5
Definition of a carer	8
Demographics	9
Mapping of carer support	11
VOCAL Survey 2013	13
National Policy Context	14
Edinburgh Policy Context	17
Local priorities for adult carers	19
Local priorities for young carers	25
Conclusion	28
Appendix 1a: Edinburgh Joint Carers' Strategy- Main Logic Model	29
Appendix 1b: Edinburgh Joint Carers' Strategy- Nested Logic Model for young carers	30
Appendix 2: The Wisconsin Logic Model	31
Appendix 3: Membership of Edinburgh Joint Carers' Strategy Working Group	32
Appendix 4: References	33
Appendix 5: National policies, guidance and legislation	34
Appendix 6: Glossary	35

Foreword by the Carers Champion, Councillor Work

"Carers are everywhere. Many people I come into contact with as a Councillor either knows of someone in a caring situation or is a carer. Carers make a very significant and valuable contribution to the people they care for and to our communities day in, day out. Over the years, I have been humbled by some of the stories carers both young and old have shared with me. Carers often tell me that their caring role can be rewarding but that it also can be challenging and brings with it many strains. This can have a negative effect on carers where they can become quite lonely, have poor health or financial problems.

Therefore, we need to ensure that carers have a life outside of caring. We must continue to support carers in Edinburgh to allow them to continue to care, if they wish to do so and where appropriate. We must do this by working in partnership, not only through the City of Edinburgh Council and NHS Lothian working together, but also through partnership working with the voluntary and private sector in order to provide better outcomes for carers.

I hope that this Joint Carers' Strategy for both young and adult carers makes a positive difference to the daily lives of carers in our city."

Councillor Norman Work, Carers Champion.

Our vision for carers in Edinburgh

Our vision for unpaid carers in Edinburgh builds upon previous local strategies for carers and takes into account the vital importance of the caring role that many carers undertake on a daily basis. Support for carers and the people that they care for must be in place to allow them to not only care with confidence, but also have a life of their own.

'Our vision for adult carers is that they are able to live healthy, fulfilling lives and that they will be valued as equal partners in the provision of care and inform decisions about carer support. Carers will be able to sustain their caring role, if appropriate and if they choose it'.

For young carers, our vision is, 'We want to ensure that young carers are enabled to be children and young people first and foremost and relieved of any inappropriate caring roles to allow them to have a quality of life'.

Introduction

The City of Edinburgh Council and NHS Lothian recognise the crucial role that carers contribute to their communities across Edinburgh. A range of good quality support needs to be available to carers at the right time and place. This is to ensure that the individual needs of carers are met. With the advent of self directed support, there will be more opportunities to have more personalised support which will empower them through improved choice and control.

Edinburgh's Joint Carers' Strategy has been developed in partnership with key local stakeholders from Health, Local Authority, the voluntary sector and carers. The strategy outlines local priorities and outcomes for carers in Edinburgh for the next three years from 2014 to 2017. This integrated approach has outcomes for carers at its centre and made use of the <u>Wisconsin Logic Model</u> to develop the strategy <u>(see appendix 1a, 1b)</u>. The aim is that this strategy will be the main roadmap for support and improved outcomes to both young and adult carers in Edinburgh.

There are **six** priority areas identified within the strategy for Edinburgh's carers:

- identifying carers
- information and advice
- carer health and wellbeing
- short breaks / respite
- young adult carers
- personalising support for carers.

These priorities were identified from the process of using the Wisconsin Logic Model with stakeholders in a working group and from a review of the previous <u>Carers'</u> <u>Strategic Action Plan for Edinburgh</u>, <u>Towards 2012</u>. In addition, a <u>mapping exercise</u> <u>of carer support</u> was undertaken to outline what support is directly available to carers across Edinburgh and also to gain an understanding of gaps in support and carer's needs. A range of sources also contributed to the development of the six priorities including local information on carers' views, census data, market intelligence, key legislation, research reports, local and national policy.

The six priorities are broad strategic areas in relation to support for carers. Each has related sub categories as below:

Priority	Sub-Categories
Identifying carers	Awareness raising and publicity, hard to reach
	groups, workforce training of carers' needs and
	issues, working with employers / education providers, carers assessments (carer support plans), carer self-identification
Information and advice	Carer training, financial planning support, welfare benefits advice, carer advocacy, online and printed information and advice
Carer health and wellbeing	Flexible carer support, one to one support, group work, emotional support, counselling, emergency planning
Short breaks / respite	Flexible and creative short breaks
Young adult carers	Transition, identification, support, employment, training
Personalising support for carers	Meeting individual needs, self-directed support, choice and control, GIRFEC framework

To meet these priorities will involve undertaking a range of activities to support carers across the city. The impact or effectiveness of these activities can be measured through outcomes. Cook and Miller (2012) define outcomes as "what matter to people using services, as well as the end result or impact of activities, and can be used to both determine and evaluate activity".

National policy and practice has shifted in recent years towards a focus on personal outcomes for people who use health and social care services (Miller and Daly, 2013). This means that what's most important to people in their daily lives and how they would like to be supported is established through an outcomes focused approach to assessment and support planning.

Through the implementation of the Joint Carers' Strategy, a range of outcomes will be met as outlined in the logic models (see appendix 1a,1b). The table overleaf outlines these outcomes for adult carers which are short term, medium term and long term outcomes.

Short term outcomes	Medium term outcomes	Long term outcomes
Carers are identified early and assessed quickly Carers have accessible	Carers report easier access to appropriate carer support or services	Carers have choice, collaboration and control in their caring roles
and up-to-date appropriate information Carers report being well informed about issues relevant to their caring role	Carers feel supported by services and have increased confidence towards their caring responsibility	Carers sustain their physical, social and mental wellbeing
Carers have improved personal safety in relation to their caring role	Carers are offered help with financial planning / benefits advice / general advice	Carers report economic wellbeing
Carers report easier access to social, recreational and therapeutic opportunities Carers are supported to address their own health and wellbeing	Carers report improved health and wellbeing Carers report improved confidence in planning, shaping and purchasing services for themselves and the person they care for	

These outcomes will be met from the various activities from all stakeholders and agencies in the form of identifying carers, referral, assessment, planning and support. There is also a nested logic model with outcomes for young carers (see appendix 1b).

Therefore, the outcomes set out the expected impact of what's happening in terms of carer support provided by all agencies across the city. By measuring outcomes, this ensures that information is collected on whether support provided for the carer makes a positive impact on their lives.

Definition of a carer

There can be many terms used to describe the role of a person who cares for someone else other than in a professional or volunteering capacity. This can range from family carer, informal carer, unpaid carer to carer. All stakeholders in the development of this strategy have adopted national carers policy and use the term 'unpaid carer', abbreviated to 'carer' which is used by most carer organisations and carers. There should also be clarity that paid workers are not 'carers', and should be referred to as care workers. In addition, carers are not volunteers. There could be volunteers who provide support to the cared for person and/or the carer, but they too should not be known as the 'carer' (Scottish Government, 2010a).

For the purpose of the Edinburgh Joint Carers' Strategy, the following definition of an adult carer has been used throughout.

"Carers provide care to family members, other relatives, partners, friends and neighbours of any age affected by physical or mental illness (often long-term), disability, frailty or substance misuse. Sometimes the 'cared for' person will have more than one condition. Some carers care intensively or are life-long carers. Others care for short periods. The carer does not need to be living with the 'cared for' person to be a carer. Anybody can become a carer at any time, sometimes for more than one person. Carers are now, and will remain, fundamental to strong families and partnerships and to resilient and cohesive communities. The lives of carers and the 'cared for' person are closely intertwined, but they are not the same" (Scottish Government, 2010a).

The following definition of a young carer, used throughout this strategy is as follows, "a child or young person aged under eighteen who has a significant role in looking after someone else who is experiencing illness or disability" (Scottish Government, 2010b).

The Scottish Government is currently consulting on proposals for <u>carers legislation</u>. Depending on the outcome of that consultation, new definitions for both adult and young carers may have to be adopted locally to be in line with implementation of any new legislation.

Demographics

The provision of support to unpaid carers is a key local and national priority. There are over 492,000 unpaid carers in Scotland (Census 2011). This is almost one in ten of the Scottish population who are involved in providing care and support to a family member, friend or neighbour to enable that person to continue to live in their own community. However, caring for someone can often continue even when the person leaves their own home and moves into a care home or other residential setting.

The Census in 2011 revealed that the number of unpaid carers in Edinburgh dropped slightly from 38,876 in 2001 to 37,859 in 2011 (See table A below). In population terms, the number of unpaid carers in 2001 represented 8.7% of the total population in Edinburgh and this reduced to 7.9% in 2011.

However, the proportion of carers who provided 20 or more hours per week of unpaid care rose from 30.6% in 2011 to 36.2% in 2011. This equates to an additional 1,826 unpaid carers in the city undertaking unpaid care for more than 20 hours per week in 2011 as compared to 2001. In addition, the proportion of carers who provide 50 or more hours per week of unpaid care also rose slightly from 20.3% in 2001 to 21.1% in 2011. In terms of numbers, 8,004 unpaid carers provide 50 or more hours per week of unpaid care, which is 21% of all unpaid carers in Edinburgh.

The Census in 2001 outlined that there were over 11,000 young carers in Scotland. For Edinburgh, there were 775 young carers. This is lower than local estimates on the number of young carers, which placed this figure much higher at 2,000 (EADP, 2012) and even as high as 5,000 (PRTC, 2009). When the Census 2011 figures on young carers are released, it may reveal much higher numbers than in the 2001 census.

Census 2011	Scotland	Edinburgh
Number of unpaid carers	492,231	37,859
Number of carers who provide 1 to 19 hours per week of unpaid care	273,333	24,137
Number of carers who provide 20 or more hours per week of unpaid care	218,898	13,722
Number of carers who provide 50 or more hours per week of unpaid care	132,082	8,004

Table A: Demographics comparison of unpaid carers in Edinburgh and Scotland (Source: General Register Office for Scotland- 2011 Census).

As demographic and social trends in Scotland project increasingly greater future demand for caring for another person, more recognition and value is placed on the growing contribution and number of unpaid carers. They provide essential quality and skilled care and should be seen as equal partners in the provision of care. Without their input, the estimated cost of replacement care in Edinburgh is valued at £771M per annum (Carers UK, 2011).

Over the next twenty years, the General Register Office for Scotland predicts Edinburgh's population will grow by 19% from 505,368 in 2013 to 603,145 in 2033. The age structure of our population will also change. This projected 19% growth in Edinburgh's population cannot be matched by corresponding increases in health and social care spending. Therefore, doing more of the same is unsustainable and demand for health and social care services needs to be actively reduced.

Mapping of carer support

A mapping exercise to support the development of the strategy was undertaken during 2013, which gained information and understanding on the direct support to unpaid carers in Edinburgh. The mapping exercise focussed on information from the period 01 April 2012 to 31 March 2013. The information returned was from a range of mainly voluntary sector organisations and projects in Edinburgh who provide direct support to unpaid carers. Out of the twenty returns, most were from carer organisations and carer projects but not exclusively.

The mapping exercise highlighted that the numbers of unpaid carers directly supported by carer support agencies was around 5,000 carers. This represents 13% of all unpaid carers in the city (Census 2011). Out of this number, 2,500 were new carers to these providers and over 8,500 unpaid carers were on mailing lists to receive information.

There is a wide range of carer support services available across Edinburgh including short breaks/respite, carer training, emotional support, support groups, advocacy and financial support and advice. However, there are notable differences between service delivery volumes of different services and between ages of carers (see table B below). However, this does not reflect the demand for some of these services. The service provision volumes in each geographical sector area were not able to be determined by the mapping exercise.

Service provision	Service volumes per annum (hours) [Adult carers]	Service volumes per annum (hours) [Young carers]
Information and advice	8,681	20
Advocacy (non-independent)	192	0
Short breaks/respite**	40,193	2,085
Emotional support	1,049	0
Groupwork/support group	1,785	4,742
One to one support	10,683	528
Counselling	1,681	90
Financial support and advice	2,116	0
Carer training-task of caring	1,176	0
Carer training-	0	0
work/education/employment		
Social and leisure opportunities	3,831	210
Other	2,642	0

Table B: Service volumes of carer support provided by carer support agencies in Edinburgh **[Please note for short breaks and respite, service volumes shown in the table are only a subset of a much larger provision which are included in the Council's statutory respite annual return]

For adult carers, the highest volume of service provision is short breaks/respite followed by one to one support then information and advice. The lowest volumes of service provision of carer support to adult carers are carer training specific to work/education/employment and counselling. For young carers, the highest volumes of service provision are group work/support groups followed by short breaks/respite. The lowest volumes of service provision to young carers are advocacy, emotional support, carer training and financial support and advice.

In terms of geographical locality of the main offices of carer support providers, the highest number (30%) were based in South West Edinburgh, with 25% based in North East Edinburgh and 25% based in other locations including the city centre and Midlothian. Only 5% had a main office in South East Edinburgh. However, service provision volumes in each geographical sector were not able to be determined by the mapping exercise.

The gaps in support as identified by the agencies who responded to the mapping exercise included a need for more dedicated emotional support work; women from minority groups; more local, flexible respite services; respite breaks for the carer and cared for person; more accessible information on short breaks and respite; support to carers aged 16 to 25 years old and more locally accessible advice, counselling, advocacy and emotional support.

Some of the issues identified by the respondents included resistance to, and a negative experience by some carers of carer's assessments/carer support plans. Another key issue for carer support providers was sustainability of funding and capacity to develop effective services. There was also a view from some around difficulties of how to identify hidden carers in the city and an apparent lack of local carer support service provision based in the South of Edinburgh.

VOCAL Survey 2013

The understanding of carers' needs in Edinburgh was also established through the recent independent VOCAL survey of carers who use their services in Edinburgh and Midlothian (VOCAL, 2013). The survey was undertaken as part of their jointly commissioned contract and separate from the mapping exercise. The survey was mailed out to over 5000 carers and received 714 responses from carers in Edinburgh and Midlothian. Key findings from the report include that 85% of carers report that the help they receive from VOCAL makes a difference to their lives. The report highlighted that 63% of carers feel that they know little or nothing about self-directed support.

The survey found that in relation to carer's assessments, 58% of carers said they would prefer someone from their local carers centre to carry out a carer's assessment, 25% said they would prefer someone from the NHS to carry out the assessment. A significant 84% of carers stated that financial planning for the future is very important to them, 74% said maximising benefits is important to them. In relation to use of technology, 74% of carers said that they have used the internet within the last three months, but 18% of carers said they have never used the internet (VOCAL, 2013).

These findings from the mapping exercise and the VOCAL survey will help inform and shape the implementation of the strategy at both a local and citywide level. It will also provide useful information for future commissioning plans for the development of carer support aligned to the identified priorities in the city.

National Policy Context

One of the key national policy documents which underpins this local carers' strategy is <u>Caring Together</u>, <u>The Carers Strategy for Scotland (2010-15)</u> and its linked young carers' strategy, <u>Getting it Right for Young Carers</u>, <u>The Young Carers Strategy for Scotland (2010-15)</u>. The Scotlish Government outline that carers should be recognised as equal partners in the planning and delivery of care and support in Scotland. The knowledge of carers, their expertise, compassion and quality of caring should be fully valued as it contributes to the overall health and social care system. Therefore, by providing adequate support to carers as early as possible to prevent a crisis, carers can continue in their caring role without significant detriment to their own health and wellbeing.

In relation to young carers, the Scottish Government are committed to ensuring that young carers can be relieved from any inappropriate caring duties and instead are supported to be children and young people first. The national strategy for young carers endorses an approach which puts the child or young person at the centre and coordinates support around them in order for their needs to be met including the impact of caring on their educational needs and own health and wellbeing.

The following headline message from 'Caring Together' has been recognised and endorsed at a local level in the development of this Joint Carers' Strategy.

"Carers are equal partners in the planning and delivery of care and support. There is a strong case based on human rights, economic, efficiency and quality of care grounds for supporting carers. Without the valuable contribution of Scotland's carers, the health and social care system would not be sustained. Activity should focus on identifying, assessing and supporting carers in a personalised and outcomesfocused way and on a consistent and uniform basis".

The significant investment to carer support in Scotland made by the Scottish Government in recent years has been welcomed and aided much progress and development across Scotland, both at a national and local level which has helped to improve support provided for carers.

However, many other national policies and legislation have had an influence or impact in shaping how carers are supported today. Below is a list of some of these (also see appendix 5):

- Social Care (Self-Directed Support) (Scotland) Act 2013
- Integration of Health and Social Care
- Welfare Reform Act 2009 and 2012
- NHS Carer Information Strategy, NHS Circular HDL (2006) 22

- Care 21 Report (2006): The Future of Unpaid Care in Scotland
- Personalisation Agenda
- Reshaping Care for Older People
- Getting It Right for Every Child

Some of the national policies such as personalisation and self-directed support will have a significant impact on the lives of carers and the people they provide care to. Personalisation can be described as a social care approach which promotes choice, control and independence for people who use services. Key elements of personalisation are active citizenship, the promotion of stronger communities and preventative action. However, this agenda applies as much to carers as those that they provide support to and highlights the interdependencies between them (Department of Health, 2010).

Self directed support (SDS) is a term that describes the different ways in which individuals and families can have informed choice about how their support is provided and how they can shape that. In social care and support, SDS allows people to have control over an individual budget, allowing them to make choices about how it is spent in order to meet their agreed health and social care outcomes. The legislation which underpins this is the Social Care (Self-Directed Support) (Scotland) Act 2013 which requires that local authorities offer people four choices on how they are able to access their social care and support. The four options are as follows:

- Option 1, the local authority makes a *direct payment* to the supported person for them to arrange their support (this can include the purchase of support);
- Option 2, the supported person chooses their support and the local authority
 makes arrangements for the support on the person's behalf i.e. they direct
 the available budget,
- Option 3, the *local authority* selects the appropriate support and *arranges support* on behalf of the supported person, and;
- Option 4, a mix of options 1, 2 and 3 for specific aspects of a person's support.

Being able to make choices is very important to carers. However, a combination of the current economic situation and reforms in welfare benefits are being felt hard by many carers. UK policies such as the Welfare Reforms are reported as having negative effects on carers and the people that they care for and the cause of much anxiety (Carers UK, 2013). Carers need the right support, information and advice to get the help they require, alleviating some of these financial pressures.

Many carers also have to attempt to balance employment with their caring role. This is the case for over three million people in the UK (Age UK, 2013). Some carers struggle to do both and often have to give up work as they may have caring responsibilities during working hours, including transport and accompanying the person that they care for to hospital appointments (Age UK, 2013). Yet, if employers have carer friendly policies in place including being able to reduce working hours or change shift patterns, this can help allow many carers balance work and caring (Age UK, 2013).

Another national policy area is prevention which is pivotal in how carers and the person they care for are supported. Due to the demands on resources, health and social care finances have been traditionally focused on meeting legislative requirements aimed at those with the greatest needs. It is now recognised that this approach is costly, both in human and financial terms. However, if support is offered at an earlier stage in people's lives, when needs begin to become known, this requires less intensive interventions over a shorter time period.

Prevention can be viewed in the context of the wider transformation of health and social care, including health and social care integration, self-directed support and the shift from institutional to community based provision. Prevention includes developing information and support to promote and improve people's quality of life, independence and engagement with their communities aiming to prevent any deterioration in their situation. Much of carer support is focused on a preventative approach and intervening as early as possible in a carer's journey.

The policy on shifting the balance of care is a central area within health and social care policy which is intended to bring about improvements in service delivery and health outcomes. Shifting the balance of care is a term used to describe change at a number of levels, including for example, shifting the location of care towards more community-based facilities. This means that services are developed and provided closer to the person's own home and community and they have more control over managing their condition. This national policy has been adopted locally in Edinburgh.

Carers have rights and much of these are underpinned by legislation such as the Community Care and Health (Scotland) Act 2002, Children (Scotland) Act 1995 and Social Work (Scotland) Act 1968. Carers' rights include the right to request their own assessment and that their views must be taken into account when an assessment is undertaken of the person that they care for. The Scottish Government is consulting on proposals for new legislation for carers, which hopefully will further reinforce both carers' rights and appropriate levels of support. The Scottish Government has also commissioned Carers Scotland and MECOPP to develop a Scottish Carers Rights Charter, which will be published later this year.

Edinburgh Policy Context

The previous <u>Edinburgh Strategic Action Plan for Carers</u>, <u>Towards 2012 (2007-2012)</u> was developed by a multi-agency partnership and through its implementation, carer support in Edinburgh was developed along with improvements in performance in areas such as increased numbers of carers assessments and increased capacity and flexibility of short breaks and respite.

A review was undertaken of *Towards 2012* and this helped to inform the Joint Carers' Strategy including the development of strategic priorities and outcomes for carers. Carer organisations and carer projects along with carers played a key role in responding to the consultation along with various professionals.

A city wide consultation was undertaken on the draft Joint Carers' Strategy from 02 September to 31 October 2013 and widely promoted through the city using a collaborative approach. There were a series of focus groups held by local carer organisations which aided feedback and encouraged carers to raise issues and complete questionnaires in their own right.

An online and printed questionnaire was used to gain feedback from the public and staff. From the 3,500 consultation questionnaires distributed, 317 were completed and returned to us. The response rate was 9%. The main respondents were carers (92%). In terms of demographics, 12% of respondents were young carers under 16 years old, only 2% were aged 16 to 25, 40% were aged 25 to 64 years old and 43% were 65 years and older. Of those respondents aged over 65 years old, 17% were aged 75 and over.

The six priorities in the draft Joint Carers' Strategy were broadly welcomed by respondents. The consultation feedback outlined some areas for improvements in carer support and included:

- More and better financial and benefits advice help for carers
- More emotional support, information and advice
- More flexible short breaks, tailored to individual needs and more breaks
- More information on short breaks
- More dedicated young adult carer support (aged 16 to 25)
- Improve transition services between young carer and young adult carer support
- Continue to provide support to young carers through schools, colleges, community centres and GP surgeries
- Drop in's for carers at GP surgeries
- Establish a carers register
- Information packs for carers at social hubs, libraries and GP surgeries

- More district nurses visiting elderly and disabled people in their homes
- Provide contact numbers for help in the house and reliable tradesmen
- Consider the needs of people from Minority Ethnic groups
- More funding for support groups

A range of local strategies, plans and policies have helped to contribute to both the development and support to carers in Edinburgh. These include the following:

- Towards 2012 Joint Carers' Strategic Action Plan for Edinburgh (2007-2012)
- NHS Lothian Carer Information Strategy (2008-2011)
- <u>Live Well in Later Life: Edinburgh's Joint Commissioning Plan for Older</u>
 <u>People (2012-2022)</u>
- Our Lives, Our Way (2007) Lothian Joint Physical and Complex Disability
 Strategy
- Edinburgh Joint Learning Disability Capacity Plan (2010-2020/25)
- Edinburgh Commissioning Plan for Adult Social Care (2011-2016)
- A Sense of Belonging Lothian's Joint Mental Health and Wellbeing Strategy (2011-2016)
- Edinburgh Alcohol and Drug Partnership (EADP) Strategy (2011-2014)
- Towards an Edinburgh Autism Strategy (2013)
- Market Shaping Strategy (2013-2018)

Implementation of local policy has enhanced and developed support to carers in the city. Carer support in Edinburgh is well developed due to a mixture of established carer organisations and carer specific support projects alongside statutory community care provision including short breaks, home care and day centres.

Most direct carer support such as advice and information, carer training, emotional support and carer advocacy is provided by the voluntary sector but not exclusively. Recent growth of these carer support services has mostly been from external funders such as the Big Lottery Fund or funding via NHS Lothian Carer Information Strategy, which has now been superseded through implementation of the National Carers' Strategy at a local level.

Local priorities for adult carers

Identifying carers

Whilst many improvements have been made over the years to improve and develop support to carers through policy and new initiatives, being a carer can be rewarding but also a complex and challenging role to undertake. The start of this journey into caring is a pivotal stage where carers can be identified either by themselves or through contact with professionals. This step is vital as it can offer an assessment of the carer's needs along with access to appropriate carer support.

Through taking a preventative approach to identifying carers, it is essential that the timing is right. Whilst some carers will self-identify, some carers do not wish to be identified as a carer, instead seeing their role as their duty. In order to achieve effective carer identification, engagement and involvement, there has to be a well performing multi-agency partnership operating which is supported through further networks that extend within and beyond our health and social care structures (CIRCLE, 2011).

We need to ensure that there are enough carer awareness and publicity materials out in our communities so that carers can self-identify and come forward for support. This includes 'hidden carers' and our more hard to reach groups such as carers from ethnic minority communities, refugees, gypsy travellers or LGBT carers. However, Flanagan and Hancock (2010) highlight that the term 'hard to reach' is a contested and ambiguous term that is commonly used within the realm of health and social care, especially in discussions around health and social inequalities. Flanagan and Hancock (2010) outline that there is a need to address health inequalities and to actively engage the marginalised and socially excluded sectors of our society in service provision.

In addition, for young adult carers, there can be many reasons for them not wishing to self-identify, including the possible stigma of a parent's physical or mental health condition or drug and/or alcohol addiction. Therefore, not only should there be more work to look at new ways to identify carers but also how providers make their services more accessible to accommodate the needs of a diverse population. We also need to explore models for undertaking carer's assessments (carers support plans) which are more outcomes focused.

Strategic Objectives:

 To ensure effective carers awareness raising along with new and innovative approaches to identifying carers including how providers can adapt services to better meet the needs of 'hard to reach' groups and hidden carers. • To explore other models of undertaking carer's assessments (carers support plans) which are outcomes focused.

Carer Outcome:

Carers are identified early and assessed quickly

Information and advice

Information and advice is a cornerstone of carer support. Without the right information and advice at the right time often heightens the anxiety felt by carers, especially at the beginning of their caring journey. So having the right person alongside carers to help them navigate through a sometimes complex array of information can often be essential. However, for some carers, their preference is online information and advice and this can be from a mixture of voluntary organisations or from statutory agency websites.

Yet sometimes specialist advice is required to help carers including financial, welfare or legal advice. A recent national report has found that seven out of ten carers were not prepared for the financial impact of caring (Age UK, 2013). Carer organisations can both refer carers onto specialist agencies or work in partnership with them to deliver local or city-wide solutions. There are also times when carers require support from advocacy services to help them make a point or raise an issue. In addition, carers can benefit from more formalised carer training courses on a wide range of subjects including condition specific or how to deal with changing relationships.

Strategic Objective:

 To continue to develop quality information and ensure provision of a range of quality advice and carer training is available across the city.

- Carers have accessible and up to date appropriate information
- Carers report being well informed about issues relevant to their caring role
- Carers feel supported by services and have increased confidence towards their caring responsibility
- Carers are offered help with financial planning, benefits advice and general advice

Carer health and wellbeing

Carers' health is often affected by tiredness, isolation and lack of their ability to enjoy social or recreational activities (OPM, 2011). In addition, caring for someone can be seen sometimes as a burden (Morris, 1993) which is negative and creates a tension towards the cared for person (Coulshed and Orme, 2012). So for many carers, their caring role is often alongside and in addition to statutory services provided to the cared for person. In turn, this can lead to carer stress as there can be a perceived loss of identity through providing that care and that they are only viewed by society as a carer (Coulshed and Orme, 2012). Yet Mackenzie and Greenwood (2012) highlight that both the positive and negative experiences of carers should be taken into account by professionals when supporting them. Thus, whilst being a carer can bring considerable challenges, there are positive elements to caring for someone that you deeply care about.

There are many ways to improve the health and wellbeing of carers and these include the provision of flexible carer support, one to one support, group work and support with emergency planning. For some carers, due to a build up of stress or anxiety, counselling services or emotional support can greatly assist their wellbeing.

Strategic Objectives:

- To make carer health and wellbeing a priority area and seek ways in which flexible carer support, practical and emotional support can be made more available to those carers who require it.
- In Edinburgh, we will work with key employers in the city to develop and promote awareness of carer friendly policies in the workplace.

- Carers are supported to address their own health and wellbeing
- Carers report easier access to social, recreational and therapeutic opportunities
- Carers report economic wellbeing
- Carers report improved health and wellbeing
- Carers have improved personal safety in relation to their caring role

Short breaks / respite

Short breaks and respite always feature highly in priorities for carers. These can be delivered in many ways including imaginative and flexible solutions to more traditional residential units. Some examples locally include the <u>'Stepping Out'</u> short breaks service which is a residential weekend away for carers. Also, there is <u>'Breakaway'</u>, a flexible break which gives families a choice about how to spend their respite time, more creatively rather than allocating them a fixed number of nights at a respite centre.

The development of more personalised and flexible short breaks for carers and the person that they care for has featured significantly in local provision for carer support in Edinburgh in recent years and is in line with <u>National Short Breaks Policy (Scottish Government, 2008)</u>. Additional funding for short breaks and respite in Edinburgh has been allocated by the Council in recent years to help meet local demand and contribute to national targets set by the Scottish Government.

National funding for development and expansion of short breaks provision has also been well received locally with many voluntary organisations securing funding from the Creative Breaks or Short Breaks fund managed on behalf of the Scottish Government by Shared Care Scotland.

Strategic Objective:

 To ensure the development of more flexible and creative short breaks as a priority for carers in the city.

- Carers report easier access to appropriate carer support or services
- Carers sustain their physical, social and mental wellbeing

Young adult carers

Within this strategy, importance will be given to how best to identify, assess and support young adult carers. The Scottish Government define young adult carers as aged between 16 to 25 years old and recognise that they have their own particular needs, but usually with limited resources to meet these needs (Scottish Government, 2010b).

One key stage for young adult carers is the transition into adulthood. This comes at a time when their peer group are either leaving school, entering training programmes, further or higher education or seeking employment. At this point, they have to juggle many demands and responsibilities including their caring role, whilst coping with their own physical and emotional changes.

We want to ensure positive destinations for young carers as they grow up and leave school. For young people who have already been identified as a young carer, it is vital that we offer a reassessment of their needs as they approach adulthood to help them manage the various transitions and associated issues in their lives. For young adults whose caring role has not been previously recognised by agencies, they should be helped to come forward and offered an assessment and support plan.

Even though they could access activities or adult carer support services, many young adult carers choose not to. This could be a combination of a lack of confidence, low self-esteem or the provision doesn't match their needs or peer group. Therefore, it is crucial that partners across all sectors consider how they can adapt and respond to improve outcomes to young adult carers.

One approach to address this situation could be a transition service with a multiagency partnership approach to offer the right type of personal support at the right time to meet the needs of young adult carers. In addition, the Scottish Government's *More Choices, More Chances* strategy advocates a multi-agency approach to support young people into positive and sustained destinations (Scottish Executive, 2006b). This approach is in line with the principles of Getting It Right for Every Child (GIRFEC). Within the approach is a focus on early identification, early intervention and re-engaging with those young people to help them back into learning, training and employment.

Strategic Objective:

• To develop a multi-agency partnership approach to identifying, assessing and personal support at the right time to young adult carers.

- Carers are identified early and assessed quickly
- Carers report economic wellbeing

Personalising support for carers

Personalising support for carers can make a significant difference to the quality of the lives of carers and the person they care for, if they receive the support that delivers the best outcomes for them, when they need it and they feel in control of that support. Coulshed and Orme (2012) outline that although the rolling out of direct payments and personalisation introduced changes in how purchasing and providing care can be achieved, this still left a vast legion of unpaid carers in society caring for someone. Now, with the introduction of new legislation in Scotland for self-directed support, carers will have much more choice and control for themselves in how their support is shaped and delivered.

Strategic Objective:

 To continue to develop how we personalise support to carers to deliver the best outcomes for them.

- Carers report improved confidence in planning, shaping and purchasing services for themselves and the person they care for
- Carers have choice, collaboration and control in their caring role

Local priorities for young carers

Identifying carers

Many children and young people do not see themselves as 'carers' and many are not identified as such by the universal services they are in contact with (Scottish Government, 2010b). The early identification of a young person as a young carer is important to enable the necessary support to be put in place. Schools play the key organisational role in identification of children's needs and issues within <u>Getting it Right for Every Child</u>. This may be as a point of contact for others who recognise a concern, or staff in the school may themselves identify that something is affecting the young person. Peers can also play a part in recognising the challenges one of their friends is facing.

Promotion of awareness about young carers among school staff and young people in all schools, as well as staff in adult services, will continue to be addressed. In addition, work will also take place with staff in other settings that young people access to raise awareness of young carers. Many young people from BME communities may have quite different expectations and understanding of appropriate caring roles and these differences should be taken into account in the identification process.

Strategic Objective:

• To ensure that in Edinburgh any young person undertaking a caring role that impacts on their development is identified by school or other staff, as appropriate, and a Getting It Right for Every Child assessment is completed.

Carer Outcome:

 Young carers are identified, assessed and supported in their educational setting and any other appropriate settings

Information and advice

As identified earlier in this strategy, information and advice is a cornerstone of carer support and this also rings true for young carers. Since many young people who are providing care do not recognise themselves as 'young carers', it is all the more important that they can easily access up-to-date and relevant information and advice

from general sources on the support that is available to them (Scottish Government, 2010b). It will be important that partners develop accessible and age relevant information for young carers and also for those working with them to use. Young people are avid users of the internet; in 2013, 93% of all 5-15 year olds used the internet (Ofcom, 2013). It is important that partners meet this desire for online information. The provision of training and advice for young carers will be to support and promote the resilience of young people rather than enabling them to be 'better carers.'

Strategic Objective:

 All young people in a caring situation in Edinburgh will be able to access good quality, age appropriate information and advice using a range of media.

Carer Outcomes:

- Young carers have accessible and up to date appropriate information
- Young carers are offered help at the appropriate time with financial planning, benefits advice and career advice

Carer health and wellbeing

The pressures on young people in general are being increasingly recognised and those young people in caring situations face further or additional pressures (Scottish Government, 2010b). Some young carers will have caring responsibilities that do not heavily interfere on their schooling, leisure time and friendships. At the other end of the spectrum however will be young carers whose health, well being and development are very significantly affected. It will be important for all partners in Edinburgh working with young carers to address the health and well being of the young carers. This will include both physical health and mental health.

Strategic Objective:

• To ensure that young carers' health and wellbeing needs are understood and are addressed by early and appropriate support.

- Young carers are supported to address their own health and wellbeing
- Young carers report improved health and wellbeing
- Carers sustain their physical, social and mental wellbeing

Short breaks/respite

Getting time away from caring and other responsibilities is important for young carers. This can include meeting other young carers on a regular basis at specialist respite group activities or residential trips away. Funding from statutory agencies has primarily enabled the regular respite group sessions to take place whilst young carer organisations have generally used charitable trusts funding to support residential activities. There is scope to widen the range of organisations that could support young carers to access respite opportunities. It should also be recognised that going on holiday or outings as a family unit can also be important to young carers.

Strategic Objective:

 To ensure that there is a wide range of attractive and appropriate short break and respite opportunities available to young carers in Edinburgh.

Carer Outcomes:

- Young carers report easier access to social, recreational and therapeutic opportunities
- Young carers receive appropriate support
- Young carers feel better supported in their caring role

Personalising support to carers

Young people should receive the responses that are indicated by the understanding that emerges from an assessment of their situation. This may range from a more flexible approach by a school based on a recognition of the young carer's circumstances, through improved service provision to the cared for person, to engaging the young carer in activities or supports that suit their situation. These activities or supports may be delivered in carer specific settings or universal settings.

Strategic Objective:

 To ensure that the responses for each young carer are consistent with the actions indicated by the assessment and contained in the Getting It Right Childs Plan.

- Young carers report inclusion in planning and shaping and purchasing services for themselves and the person they care for
- Carers have choice, collaboration and control in their caring roles

Conclusion

The Joint Carers' Strategy will provide the roadmap for carer support in Edinburgh for the next three years and will guide the future commissioning of carer support. It will help provide focus and direction to all stakeholders to work collaboratively to deliver and measure the best outcomes for carers regardless of their age.

The implementation of the strategy will be regularly monitored and performance managed through the development of an action plan. Reporting on progress will occur through the local carer planning and Committee structures that are in place in the city.

To conclude this strategy, we have included a selection of some of the voices of carers from consultation.

"Most people only ask for help when a crisis arises....can only be helped by early intervention."

"There is not enough support for carers. A lot of people don't know where to go for help."

"For young carers, the priority should be support as it's not about making them better at caring, it's about letting them be children first and foremost."

"It's important for carers to realise that they do have choices and rights and that there is support out there."

"It is extremely important that carers continue to be supported and are kept fully informed of changes."

"Every carer should have support and respite and a bit more financial support."

"Support to carry on working, not to have to give up"

"Support should be proactive and not reactive"

"Carers want to be taken seriously."

Appendix 1a: Edinburgh Joint Carers' Strategy- Main Logic Model

Below is a simplified extract. For full versions of the logic models, please download from www.edinburgh.gov.uk/jointcarersstrategy

INPUTS	
The City of Edinburgh Council	
NHS Lothian	
Voluntary Sector	

Priorities
Identifying carers
Information and advice
Carer health and wellbeing
Short breaks/respite
Young adult carers
Personalising support for carers

Activities	Participation	
Identification/recording of carers		
	Adult carers	
Awareness raising amongst employers,	Young Carers	
employees, volunteers	Young adult	
Communication strategy in support of capacity	carers	
building	'Cared for' person	
Promotion of	Service users	
personalised support	Service providers	1
Promotion of safety in home	Employers	
Mainstreaming access	Employees	П
to support	Students	
Promotion of positive	Volunteers	
health outcomes	Trainers	
Development of financial support services		

Sh	ort Term Outcomes	Medium Term Outcomes	Long Term Outcomes
Call up info	rers are identified early discussessed quickly rers have accessible and to date appropriate ormation rers report being well ormed about issues evant to their caring role rers have improved resonal safety in relation to ir caring role rers report easier access social, recreational and rapeutic opportunities rers are supported to dress their own health discussions.	Carers report easier access to appropriate carer support or services Carers feel supported by services and have increased confidence towards their caring responsibility Carers are offered help with financial planning/benefits advice/general advice Carers report improved health and wellbeing Carers report improved confidence in planning, shaping and purchasing services for themselves and the person they care for	Carers have choice, collaboration and control in their caring roles Carers sustain their physical, social and mental wellbeing Carers report economic wellbeing
		101	

Appendix 1b: Edinburgh Joint Carers' Strategy- Nested Logic Model for young carers

Below is a simplified extract. For full versions of the logic models, please download from www.edinburgh.gov.uk/jointcarersstrategy

The City of Edinburgh Council

NHS Lothian

Voluntary Sector

Priorities

Identifying carers

Information and advice

Carer health and wellbeing

Short breaks/respite

Young adult carers

Personalising support for carers

Activities	Participation
Identification, assessment and recording of young carers	Young Carers
Awareness raising amongst	Young adult carers
schools/other educational establishments / employers/ GPs other Healthcare providers	'Cared for' person
Development of whole school policies for young carer support	Schools/other educational
Provide staff training	establishments
Promotion of whole family support	Statutory and voluntary service
Provide activities which deliver positive outcomes against the	providers
wellbeing indicators Provide support with transition	Specialist young carer services
Provide informal educational opportunities	GP's/Healthcare
Provide respite from caring role	providers
Promote children's rights and the	Employers/Employees
UNCRC	Students/Volunteers
	Trainers

Short Term Outcomes	Medium Term Outcomes	Long Term Outcomes
Young Carers are identified, assessed and supported in their educational setting Young Carers have accessible and up to date appropriate information Carers report being well informed about issues relevant to their caring role Young Carers report easier access to social, recreational and therapeutic opportunities Young Carers report reduced barriers to participation in formal and informal education Young Carers are supported to address their own health and wellbeing	Young Carers receive appropriate support Young Carers report improved health and wellbeing Young Carers feel better supported in their caring role Young Carers are offered help at the appropriate time with financial planning, benefits advice and career advice Young carers report inclusion in planning and shaping and purchasing services for themselves and person they care for	Carers have choice, collaboration and control in their caring roles Carers sustain their physical, social and mental wellbeing Carers report economic wellbeing

Appendix 2: The Wisconsin Logic Model

In order to develop the Edinburgh Joint Carers' Strategy, the working group agreed to make use of the <u>Wisconsin Logic Model (see appendix 1a,1b)</u>. The following summarises its value as both a planning and evaluation tool:

- it brings detail to broad goals
- helps to identify logical gaps in strategies
- it is outcomes focused
- builds consensus about what the strategy is and how it will work
- makes underlying assumptions explicit
- helps to clarify what is appropriate to evaluate
- summarises complex strategies to communicate with stakeholders
- enables effective competition for available resources.

The logic model for the Joint Carers' Strategy was developed over many facilitated sessions, taking into account both existing national and local outcomes for carers. The development of the logic model allowed reflection on the current situation and proposed new short term, medium term and long term outcomes to be developed for carers. Priorities were then established along with activities and illustrative measures of performance.

Appendix 3: Membership of Edinburgh Joint Carers' Strategy Working Group

Group	
Name	Organisation
Gordon Dodds [Chair]	Planning and Commissioning Officer (Carers), Integrated Carers Team, Health and Social Care
Elizabeth Anne Ewing	Carers Reference Group
Seb Fischer	Chief Executive, VOCAL
David Hoy	Commissioning Officer, Children and Families
Alison Jarvis	Carer Lead Officer, NHS Lothian
Carole Kelly	Carer Services Development Manager, Integrated Carers Team, Health and Social Care
Marion Lacey	Facilitator, Social Value Lab (funded by the Scottish
•	Government's, Developing Markets Programme).
Wendy Laird	Carers Reference Group
Madi Martin	Carer Coordinator, Integrated Carers Team, Health and Social Care
Ruth MacLennan	Manager, Care for Carers
Suzanne Munday	Director, MECOPP
Margaret Murphy	Manager, Edinburgh Young Carers Project
Lynne Porteous	Facilitator and Early Intervention Strategic Manager, Children and Families
Jacquie Robertson	Planning and Commissioning Officer (Carers), Integrated Carers Team, Health and Social Care
Donny Scott	Service Manager, Family and Community Support, Children and Families

Appendix 4: References

Age UK, Carers UK et al (2013) Prepared to care? Exploring the impact of caring on people's lives, London, Carers UK.

Carers UK (2011) Valuing Care: Calculating the value of carers' support, London, Carers UK.

Carers UK (2013) State of Caring 2013, London, Carers UK.

CIRCLE, University of Leeds (2011) New Approaches to Supporting Carer's Health and Wellbeing: evidence from the National Carers' Strategy Demonstrator Sites programme, Leeds, CIRCLE, University of Leeds.

Cook, A. and Miller, E. (2012) *Talking Points, Personal Outcomes Approach- Practical Guide*, Edinburgh, Joint Improvement Team.

Coulshed, V. and Orme, J. (2012) Social Work Practice, Hampshire, Palgrave.

Department of Health (2010) Carers and personalisation: improving outcomes, London, Department of Health.

Edinburgh Alcohol and Drug Partnership (EADP) (2012) Assessment of needs and review report on children and families affected by substance misuse.

Flanagan, S.M. and Hancock, B. (2010) 'Reaching the hard to reach'- Lessons learned from the VCS (Voluntary and Community Sector) A qualitative study, *BMC Health Services Research*, 10:92.

Mackenzie, A. and Greenwood, N. (2012) Positive experiences of caregiving in stroke: a systematic review, *Disability and Rehabilitation*, 34(17), pp.1413-1422.

Miller, E. and Daly, E. (2013) *Understanding and measuring outcomes: the role of qualitative data*, Glasgow, IRISS.

Ofcom (2013) Children and parents: media use and attitudes report, London, Ofcom.

OPM (2011) Support Needs of Older Carers in Edinburgh, London, OPM.

Princess Royal Trust for Carers (PRTC) (2009) *Mapping of services to young carers in Scotland,* Glasgow, PRTC.

Scottish Executive (2006a) Care 21 Report: The Future of Unpaid Care in Scotland, Edinburgh, Scottish Executive.

Scottish Executive (2006b) More Choices, More Chances, Edinburgh, Scottish Executive.

Scottish Government (2010a) Caring Together, The Carers Strategy for Scotland (2010-15), Edinburgh, Scottish Government.

Scottish Government (2010b) *Getting it Right for Young Carers, The Young Carers Strategy for Scotland (2010-15),* Edinburgh, Scottish Government.

VOCAL (2013) VOCAL Carer Survey 2013, Edinburgh, VOCAL.

Appendix 5: National policies, guidance and legislation

- Public Bodies (Joint Working) (Scotland) Bill
- Self Directed Support Strategy (2010)
- The Keys to Life (2013) National People with Learning Disabilities Strategy
- Short Breaks (Respite) Guidance: CCD 4/2008
- Community Care and Health (Scotland) Act 2002
- Changing Lives: 21st Century Social Work Review
- The National Programme for improving Mental Health and Wellbeing, including the 'Choose Life' and Anti-Stigma strategies
- Scottish Strategy for Autism
- The Road to Recovery National Drugs Strategy
- Changing Scotland's Relationship With Alcohol (A Framework for Action)
- Reducing Delayed Hospital Discharge
- Equally Well Reducing Health Inequalities
- National Outcomes Single Outcome Agreement / Talking Points
- Shifting the Balance of Care
- Better Health, Better Care

Appendix 6: Glossary

Advocacy	Advocates speak for people who are unable to speak up for themselves, or feel that others may not be listening to their views and opinions. Advocates can act on a peson's behalf so their voice is heard and their rights and interests are protected. Advocates operate independently of other services.
BME	Black and Minority Ethnic community
community	
Commissioning	The process of planning and delivering services. This involves understanding needs, planning how these should be met and putting services in place, either by delivering services directly or purchasing them.
Direct Payments	Payments from the Council so that people have the means of controlling their own care at home, allowing more choice and flexibility. They can be used, for example to employ a personal assistant; buy agency services from private providers, or services from a voluntary organisation; buy local authority services, and so on. See also self directed support .
LGBT	Lesbian, Gay, Bisexual or Transgender.
Personalisation	An approach to social care which gives people greater choice, control and flexibility over the kind of care they want. Choices may include a direct payment managed by a third party, directing an individual budget, support from the local authority or from another provider. The choice can also be a combination of these. See also self directed support.
Prevention	To develop services and provide information and support to promote and improve people's quality of life, independence and engagement with their communities and to prevent any deterioration in their situation. There are three levels of prevention.
	 Primary Prevention – supports aimed at people who have little or no particular social care needs or symptoms of illness but who can support the achievement of outcomes related to the maintenance of independence, good health and wellbeing. Secondary Prevention – supports aimed at people identified as 'at risk' and who want to halt or slow down any deterioration and actively improve their situation. Tertiary Prevention – supports aimed at helping people who want to minimise the impact of disability or deterioration from established
	health conditions or complex social care needs.
Self directed support (SDS)	A term to describe the ways in which individuals and families can have informed choice about how the way support is available to them. It includes a range of options for exercising these choices, including direct payments .
Third sector	An umbrella term for a diverse range of organisations such as voluntary groups, charities, social enterprises, community organisations, etc.