Time to think about...
Shaping Support for Older Family Carers of Adults with Learning Disabilities in Planning for the Future
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Executive summary

Context
Over the last 15-20 years, recognising and responding to the needs of carers has steadily gathered momentum, evidenced through developing legislation to give carers rights, implementing policy to benefit carers directly and through an increasing body of research to inform practice. Unpaid carers (family and/or friends) are providers of care and so the economic argument for continuing to support carers is unequivocal; both at a local and national level.

Demographic changes have also led to a specific group of carers now wanting support in their own right (older family carers of adults with learning disabilities) as for the first time in history, adults with learning disabilities are outliving parents. Paradoxically, whilst advancements in healthcare can be celebrated, older carers now worry about what will happen to their sons or daughters when they are no longer able to provide care. Securing housing as well as funding for care packages is a concern and supporting older carers to think about making plans for the future requires a very personalised, individual response. Ensuring the future housing needs of adults with a learning disability (in terms of identifying numbers and planning) continues to be a priority for South Lanarkshire Council’s Local Housing Strategy.

Research aims
Building on the recommendations from independent research carried out in 2005 for South Lanarkshire Council into the needs of older family carers, a strategic approach has been developed in supporting this carer group in thinking about making plans for the future, entitled Time to Think About… A dedicated Social Worker post was created to support this work.

The approach has taken the form of offering individual visits to older carers across South Lanarkshire to explore issues in relation to future planning, to pass on information, answer carers’ questions, ‘signpost’ onto other agencies and to record carers’ wishes for the future with three key aims:

- To increase the support offered to older family carers
- To raise awareness of older carers’ needs
- To influence the future planning process at South Lanarkshire Council

Research methods
An ‘Action Research’ approach was taken with the intention of bringing about changes as a result of carers’ participation in the research and learning process. Time to Think About… ultimately seeks to shape support for older carers through identifying gaps in provision that can be evidenced and in working to then address these. The target population was older family carers in South Lanarkshire who were supporting an
adult with a learning disability living in the family home. 166 visits were completed over a four year time frame (given the four year time frame, individual circumstances may have changed and practice revised during this time - these variables should be taken into account when reading the report). Carers who might benefit from this dedicated support were visited by the dedicated worker and other Social Workers within the local authority’s area teams. The data collated is subjective in nature but nevertheless provides a good insight into the support older carers require for future planning and in shaping service design to meet the needs of ageing adults with learning disabilities and their families. Visits took the form of semi-structured interviews covering legal issues, housing, emergency planning, Carers’ Assessments, support for carers within South Lanarkshire and carers’ health issues.

Responses from carers were recorded on a proforma for later coding and analysis. An information pack was developed to accompany this piece of work. In total, 195 visits were offered, 85% of respondents agreed to take part with 166 visits completed (n=166). Carers were all aged over 50 and the vast majority were White, Scottish in ethnic origin and from rural and urban areas across the authority. Some carers were interviewed as couples.

**Key findings**

Time to Think About… illustrates that older family carers do want to be supported in thinking about planning for the future. This is evidenced by the high take-up rate when carers were offered the opportunity to explore options around what is for many a very sensitive subject to address. A personalised yet fairly informal approach was welcomed and this is illustrated by the high take-up rate with the visits juxtaposed with a much lower number of carers attending information workshops. Though staff were concerned about raising expectations, many carers passed on that a visit focussing on the carer as opposed to the service-user (though not in superseding the wishes of service-users) was welcomed as good practice.

**Legal issues**

In discussing legal rights, Time to Think About… saw an increase in the amount of carers taking a proactive approach in seeking independent legal advice, though older carers heavily involved in carers’ rights were not always those who were most proactive and for some older carers, dealing with legal issues such as applying for Guardianship remains a daunting thought. Advising carers of their legal entitlement to a Carer’s Assessment also saw an increase in the number of Carers’ Assessments completed, reinforcing the argument that practice and timing are important factors in offering Carers’ Assessments.

**Housing options**

Older family carers want a range of housing options on offer and welcome the opportunity to plan ahead before a crisis occurs though for some families unable to let go, crisis intervention will always be inevitable. Just over a third of carers were wanting their relative to remain in the family
home but 37% of those questioned identified the need for 24 hour support for their relative and meeting the care needs of individuals (more and more with profound and multiple learning disabilities) little remains a financial challenge. There is a need to look at supporting carers and service-users to ‘plan’ in relation to housing options as an entire generation of unpaid care decreases but in also accessing the desired option at a time of need. Thorough planning should lead to a decrease in crisis intervention for older carers. Older carers still state they are unaware of the housing options available and how to negotiate their way through applying for housing through the local authority with a reliance on Social Workers to assist with this process. Again, through Time to Think About… some carers were keen to begin the process of supporting their relatives with a housing application and carers spoke of discussing housing options and care packages with family members where possible. Housing concerns form only a part of this report and the report focuses areas for discussion in relation to housing issues. The qualitative data retrieved is a starting point for further quantifying housing demand for people with learning disabilities.

**Support**

Good partnership working is central to supporting carers within South Lanarkshire and older carers continue to be well supported by South Lanarkshire Carers Network and The Princess Royal Trust Lanarkshire Carers Centre. Some older carers have benefited from a personalised, ‘carer-centred’ response (solution focussed) to their specific needs through the dedicated post for older carers but this intensive support is difficult to offer in larger numbers. Research suggests that carers do benefit from dedicated support (emotionally and practically) and that responses should fit around the carer and not vice versa. Carers continue to access support through a range of sources yet reliance on family members over formal carers’ support is evident.

**Emergency planning**

A reliance on family members in an emergency remains high with almost a third of carers giving this response. Very few formal plans are in place and this is a real worry for older carers. The majority of those questioned stated they would rely on either family or Social Work Resources to ‘step-in’ in an emergency but the need to look at supporting older carers at a time of crisis (indeed carers across the board) remains clear. A practical approach with carers should be supported by a strategic response from health and social care partners.

**Carers’ health**

44% of older carers described their health as ‘good’ but responses are subjective and almost half of those questioned have significant health issues. Carers often link their sense of wellbeing to the support offered to the person they are providing care for. It would be interesting to note whether having dedicated carer support (very much in the shape of carer advocacy) does increase a carer’s overall sense of emotional and physical wellbeing and this would need further research.
**Recommendations**

Given the points for discussion/good practice made at the end of each section and the justification put forward for these, broad recommendations will be made here as South Lanarkshire Council should take note of the specific points made in terms of shaping service design. Recommendations are as follows, derived solely from the data analysis and emergent themes:

- South Lanarkshire Council should continue the development work to better address the needs of older family carers.
- Findings from this report should be disseminated to staff within South Lanarkshire Council, to partners and carers.
- Consideration should be given to researching and developing a toolkit for supporting older family carers to standardise practice.
- Legal provision should broadly be addressed as part of the review process as it stands so that older carers can be supported in future planning.
- The quality of the Support Plans/Carers’ Assessments offered to older carers (and other carer groups) should be monitored alongside numbers.
- Emergency planning for carers should be developed and reviewed with carers, partners and colleagues.
- Older carers’ health and social care needs should be taken into account when looking at future planning and a consistent, strategic approach taken.
- Consideration should be given as to how a growth in the numbers of adults with learning disabilities requiring housing and support can be met. Work should start on collecting data in light of this report.
- Older carers should continue to receive good, up-to-date, timely information in relation to future planning.
- Consideration should be given to whether the current practice model in working with older family carers of adults with learning disabilities should be reviewed with a view to a more individualised response to working with carers.

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**Introduction**

Time to Think About... is a specific approach to supporting older family carers of adults with learning disabilities in thinking about planning for the future. Over a four year period, a series of visits to older family carers (within South Lanarkshire) have been completed to explore concerns with carers, to answer questions, provide information and offer practical support where identified. Alongside individual visits, further practice developments have ensued as a result of working specifically with this carer group and findings from the visits form the basis of this report. Time to Think About... may be termed ‘action research’. It is embedded in an evidence-based approach but through doing; through action, ‘an orientation of inquiry that seeks to centre a quality of engagement, of curiosity, of question-posing through gathering evidence and testing practices’, (Reason and Bradbury, 2006:xxi). Time to Think About... has three very clear aims:

1. To increase the support offered to older family carers
2. To raise awareness of older family carers’ needs
3. To influence the future planning process at South Lanarkshire Council

**Background**

In 2001 a small number of family carers of adults with learning disabilities established a group in South Lanarkshire. The group called itself The COLD Group (Barton and Clark, 2011), which stood for ‘Carers of Learning Disability’. Historically, carers of adults with learning disabilities have been supported (locally) through branches of ENABLE Scotland (in England through MENCAP) but there was the need for more than ‘support’; for carers to become involved at a local level in shaping services for themselves and their relatives. The COLD Group broke up in 2004 but a former Social Worker and her friend (Madge Clark and Jeanette Kelly) went on to form their own group, The Murray Owen Older Carers’ Group (Clark, 2011), which sought to campaign for the same rights for adults with learning disabilities living in the community as those who were discharged from the long stay hospitals and hostels. As well as petitioning the then Scottish Executive the group also approached South Lanarkshire Council to ask for independent research to be carried out into the needs of older family carers (Martin and Johnston, 2005). This research was the only detailed study at that time in Scotland (Charter for Change, 2010a) and in many ways began a move towards raising awareness of the need to look at supporting this group of carers, not least because for the first time in history adults with learning disabilities are outliving their parents, ‘The vast majority of adults with learning disabilities who live in private households live with their parents. Many adults with learning disabilities living at home do so with parents who are aged 60 and over. This demographic picture is one that requires greater attention by public authorities if learning disabled adults are to live full lives. The needs of ageing parental carers also need to be planned for, to avoid crisis situations when they can no longer continue to care for their middle aged/elderly son or daughter’ (Quarriers, 2008:3). It could
be argued that through the ageing process older people may anticipate taking on a caring role in some form; that there may be an ‘expectation’ of illness or disability in older age (Heron, 1998) but for older carers of adults with learning disabilities the caring role, by the time they reach older age, is long established and entering older age as a provider of care and not as a recipient now needs to shape services, particularly as the two roles may become intertwined with us seeing an increase in long-term conditions. The ageing process is of concern for the older carers who worry about where their sons and daughters will live in the future and of the level of paid care they will receive but should also be of concern to the local authorities who currently rely on a wealth of older carers meeting many care needs at little cost, with the situation described by MENCAP in their 2002 report as a ‘housing timebomb’.

**Approach**

The report commissioned by South Lanarkshire Council (Martin and Johnston, 2005) made seven key recommendations, essentially as a baseline from which to move forward (2005:24). One of the recommendations was to consider a ‘transitions post’ (2005:31) to support this group of carers and in 2006 a Social Worker from the Council’s Older People’s Team took up this post.

Whilst the role is multifaceted, a key focus over the last five years has been in overseeing individual visits to older family carers to open up discussion in relation to future planning as identified in Martin and Johnston’s report (2005:31) with the need to take a micro level approach. Embedded at the heart of practice is South Lanarkshire Council’s strong commitment to values; that carers are now recognised as key partners in providing care, indeed as equal partners (South Lanarkshire Council 2010:2). 166 visits to older family carers have taken place within South Lanarkshire specifically as part of this approach and the responses gained from carers will be presented to the local authority with a view to shaping service design. Findings will be supported through the use of wide ranging literature and in taking into account informal feedback from carers and partner agencies. Time to Think About... though cannot possibly stand alone as an ephemeral, ‘one off’ piece of work (as perhaps it was set out to). Whilst it has a clear focus in terms of looking at future planning, this micro approach is arguably pushing for a macro response; findings from the report may be of interest to The Scottish Government as research-informed practice recommendations will be made.
Who are older family carers?

South Lanarkshire Council can be commended for its commitment to working with this specific group of carers but who is this group and why offer them this specific level of support? In general,

- Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

(Carers Scotland, 2011b)

The term ‘older carer’ in this report refers to carers aged 50 and over who are supporting a person with a learning disability. Older carers of a person with a learning disability are a unique group in that they have been ‘caring’ for many decades but in some respects share much in common with carers supporting people from other client groups, for example most wish to be involved in shaping their relative’s care package, treated with respect by professionals, to be consulted by social work and healthcare professionals, to be listened to and to have their expert knowledge of the person they care for recognised. They are a group who have lived through a huge shift in policy from a time when adults with learning disabilities were often placed in ‘institutions’ on the fringes of the wider society and in this sense share much in common with family carers of people with mental health problems who have also lived through the closure of psychiatric hospitals and asylums.

Many carers speak positively in relation to how things have changed for the better but concerns about meeting care needs in the community remain a worry for many carer groups and is not unique to older family carers. What is unique is that older family carers are ‘lifelong’ (ENABLE Scotland, 2008), are an ageing group (many with their own care needs) still offering huge amounts of unpaid care and arguably, because of the ageing process, accepting and adapting to policy shifts is often traumatic. Growing pressure from carers of adults with learning disabilities locally and nationally is very much rooted in not only the changes in legislation but also in societal changes; this group now in many ways is challenging the ‘social construct’ (MacLean et al. 2002:13) of the carer through placing greater demands on services for more support (for example, older carers of working age (50-65) have gained the right to request flexible working under The Work and Families Act 2006).
A learning disability (as defined by The World Health Organisation) meets three criteria, worldwide:

- Significant limitations in intellectual functioning
- Significant limitations in adaptive behaviour
- A manifestation of these symptoms before adulthood

(World Health Organisation, 2007:17)

In 1834 the Poor Law was passed shaping for the first time a national move to house people with learning disabilities and people with mental health problems in institutions. The ideology was arguably well founded, intending to improve the lives of vulnerable people, ‘They [institutions] were often developed by the radical free thinkers of the day and were a genuine attempt to improve conditions for their residents. Asylums were often built in idyllic settings, they were light and clean and were often a great improvement on the common living conditions of the time’ (MENCAP, 2011). The asylums though were authoritarian where people were not treated as individuals but cared for collectively in meeting basic needs. The 1913 Mental Deficiency Act for the first time recognised the difference between adults with learning disabilities and adults experiencing mental health problems. People with learning disabilities had to be certified as ‘mentally defective’ to be admitted to an institution with the intention of segregating them from the wider society. By
1914 asylum numbers had risen to 2000 (Hopkins: 2006), marketed as places of refuge often in remote, rural areas where the ‘inmates’ were often sterilized. The period between the two world wars saw the largest increase in numbers admitted to institutions as the Eugenics movement gathered pace. Gogarburn Hospital on the outskirts of Edinburgh opened in 1924 with just 24 women admitted and provides us with an image of institutional care, ‘...characterised by a custodial, hierarchical hospital regime marked by its self-sufficient nature; having its own farm, laundry and workshops for instance’ (Ingram, 2003:18). By 1948 it is estimated that 540 patients were there (2003:4). The 1959 Mental Health Act further distinguished between mental illness and the new term of ‘mental subnormality’. 1968 placed a duty on local authorities to provide services to ‘the mentally handicapped’ with the implementation of the Social Work (Scotland) Act. It was not until the White Paper was published (Better Services for the Mentally Handicapped) in 1971 (MENCAP, 2011) though that things began to improve. This advocated the closure of the long stay hospitals by 50% by 1991. This shift in policy came as a consequence of The Howe Report in 1969 highlighting a cover-up of abuse at Ely Mental Hospital in Cardiff. Similar stories of cruelty and abuse followed and the momentum to close the long-stay institutions gathered pace. The NHS and Community Care Act sealed the move away from institutionalised models of care and it was in 1995 that carers for the first time gained their own rights through The Carers (Recognition and Services) Act. The first Scottish strategy for carers was published in 1999 focussing on information, short breaks and accessing services. Building on the strategic aims, The Community Care and Health (Scotland) Act 2002 then placed a statutory duty on local authorities to inform carers of their right to an assessment of their own needs. A major criticism of the legislation though is that there is no legal requirement to provide services to carers, only to take their needs into account if providing a ‘regular and substantial’ amount of care. In 2006, Care 21 – The Future of Unpaid Care in Scotland was published (Scottish Executive, 2006b) which sought to regard carers as ‘key partners’ and focussed on four key priorities; young carers, carers’ health, training and respite. In 2010 Caring Together the new carers’ strategy for Scotland was published with an emphasis on carers’ rights, as carers as equal partners but for the first time crucially citing the need to address the housing issues facing adults with learning disabilities as their carers age. 2012 also sees a review of The Same as You? (learning disability guidance), which carers and service-users eagerly await, not least because there is now an expectation that the focus will shift to those living in the community, the majority of whom live with their older parents but amongst a backdrop of challenging economic times.
Demographics

Nationally

There are 657,300 carers in Scotland (Scottish Household Survey, 2007-2008 cited in Caring Together 2010:21) and South Lanarkshire has the fifth largest population of carers at 38,023 (Scottish Household Survey, 2007-2008 cited in Caring Together 2010:128). It is estimated that carers save the Scottish economy just over 7.5 billion each year (Caring Together, 2010). Scotland’s population of people aged 65 and over is projected to rise by 62% by 2031 (Caring Together, 2010) resulting in an additional 25% demand for health and social care services by 2031 (Caring Together, 2010). We are also likely to see a cultural shift in the age of carers in Scotland in the next ten years as the proportion of carers from black minority ethnic (BME) backgrounds grows older. MECOPP in Edinburgh (The Minority Ethnic Carers of Older People Project) has seen its numbers grow from 80-360 and now also offers support to carers of adults aged 25 and over (Williams, 2007). Demographic challenges continue to drive the carers’ agenda and Caring Together highlights that more children with additional support needs are being cared for at home (2010:13) but also suggests that increased diagnosis and reporting may be contributable factors. It is likely that we will see the numbers of carers of children (and of adults) with autism rise as a result of these factors. Indeed, within South Lanarkshire a parent/carer led group has been set up, ‘Information for Carers of Children with Additional Needs’ (ICCAN) to offer information and support to this growing number of carers.

A study carried out by Lancaster University’s Centre for Disability Research suggests that the number of adults with learning disabilities needing social care is set to soar by between 3.2% and 5.5% on average from 2009 to 2026 (Community Care, 2008:6). In Scotland, there are around 125,000 people with learning disabilities (The Same as You? 2000:6) but it is estimated that only 30,000 are in regular contact with statutory services. It is suggested that 25% of people with a learning disability have a carer aged 65 and over (Grampian Strategy for People with Learning Disabilities 1997 cited in The Same as You? 2000), but the actual ages of carers are not recorded at present, only age ranges. Recording the ages of older carers of adults with learning disabilities would be a good starting point for planning services and in aiming to meet the needs of this group. Quarriers’ report (2008:4) criticised the ‘poor and inconsistent’ approach by local authorities in collecting data on adults with learning disabilities and their carers. Caution should be applied though in collecting statistics that are not directly used to shape services; it should be possible to provide good planning based on a relatively small set of statistics, which is what South Lanarkshire is working towards at a local level.

Socio-economic disadvantage

Carers of adults with learning disabilities are at greater risk of socio-economic disadvantage (Emerson, 2003) and are likely to report significant health issues, which can place even more pressure on the
caring role (Martin and Johnston, 2005). Adults with learning disabilities are also likely to be exposed to, ‘common social determinants of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination’ (Emerson and Baines, 2010:11). Whilst an ageing population can be viewed as a success story in terms of health and well-being, there are added pressures on NHS partners in meeting the needs not just of older carers, but of adults with learning disabilities as they now age.

Dementia for example is approximately four times more common in adults with learning disabilities when compared to the rest of the population (Cooper 1997 cited in Health Needs Assessment Report 2004:28). Physical ill health is also more common in older adults with learning disabilities, arguably less easy to detect if not reported and older adults with learning disabilities may also lack close family support if older parents have passed away (2004:29). NHS Lanarkshire’s Community Learning Disability Team sought to tackle the health inequalities of older adults with learning disabilities through the creation of a Transitions Post within the team to cover the life span of an ageing person with a learning disability and greater support has been offered to older family carers through the Acute Liaison Nurse Practitioner; a link with South Lanarkshire’s three main hospitals, with ward staff, carers and adults with learning disabilities. Whilst we commend the medical advances made in improving the health of adults with learning disabilities, sadly, many older carers will still hope that their son or daughter passes away before they do (ENABLE Scotland, 2009) because as much as families can plan, there will always be the uncertainty of what will actually happen. Carers today who have seen their sons and daughters ‘settled’ in the community with large care packages funded partly through Independent Living Fund (ILF) monies are now looking to the planned demise of the fund and wondering how the packages will be sustained (PAMIS, 2010). For parents and carers of younger adults with profound and multiple learning disabilities (where care packages are likely to be costly), this is very worrying as to how they will be funded when previously applications to the ILF could be made.

**Within South Lanarkshire**

South Lanarkshire Council knows of 1134 adults with a learning disability (South Lanarkshire Council, 2011). In 2005, the number of older carers known to the local authority stood at 332 equating to approximately 40% of adults with learning disabilities living in the family home (Martin and Johnston, 2005). However, retrieving data from within Adult and Older People Services, the Council is now in touch with approximately 600 family carers of adults with learning disabilities (some younger than 50) as data is captured as young people with additional support needs move through to Adult and Older People Services. The mailing list was used as a baseline from which to develop Time to Think About... and in some ways demonstrates that good planning can be done with a small set of numbers.
Time to Think About… builds on many of the recommendations made by Martin and Johnston (2005:24) in the report commissioned by South Lanarkshire Council. They found that communication remained an issue for older family carers and suggested that an accurate mailing list be compiled as a starting point, which is now updated annually. A further recommendation was that the two departments of Housing and Technical Resources and Social Work Resources should work together in recording and interpreting data, so as to, ‘anticipate need and respond effectively’ (2005:25). Concerns were raised by older family carers of not knowing what housing options were available and how to access these. Work has progressed in this area but there remains further work to be done. They recommended that an individual approach to working with families should be taken forward (through creating a dedicated post and through Time to Think About… this has also been achieved). A further recommendation was to offer information fayres, which again have been organised once a year since the publication of the 2005 report with a Housing Information Fayre attended by 111 people for example. A recommendation for better information was made and a resource pack to accompany Time to Think About… was produced with (and was well received by) older carers. The resource pack was a joint approach from colleagues at South Lanarkshire Council working across Social Work Resources, Legal Services and Housing and Technical Resources. This was sent to all carers on the mailing list, to colleagues and partner agencies. A further recommendation was made to address emergency planning, which South Lanarkshire Council is currently developing (see Appendix 5). Greater flexibility within day opportunities was also highlighted and the need to review with older families was identified as a priority; that this should constitute a cycle of support.

**Methodology**

Time to Think About… is a strategic approach to supporting older family carers of adults with learning disabilities in thinking about future planning. It builds on the recommendations made from independent research commissioned by South Lanarkshire Council six years ago (Martin and Johnston, 2005). It forms a series of visits completed over four (almost five) years to older carers to explore the following issues: legal provision, housing options, emergency planning, Carers’ Assessments, support for carers and carers’ health concerns. These topics were identified as key areas to focus on in the report completed by Martin and Johnston and are further supported by wide-ranging literature addressing the concerns of older family carers in planning for the future. The visits (though semi-structured interviews) were informal in nature and the micro approach recommended by Martin and Johnston was used deliberately to put carers at ease on a one-to-one basis with the Social Worker conducting the interview, to allow for carers to ask questions, gain information and feel supported in talking through what for some is a very difficult issue. Data collated from the interviews forms the basis of this report and the recommendations made to South Lanarkshire Council.
Older family carers were identified for visits between the Social Worker (the author of this report) and each Team Leader in South Lanarkshire’s Adult Teams. The first team to engage with this piece of work was East Kilbride, followed by Hamilton, Blantyre, Larkhall, Clydesdale and lastly the Rutherglen and Cambuslang team. The Social Worker developed a briefing for colleagues in approaching Social Workers within the Adult Teams to help undertake visits (see Appendix 1 and 2) and met with each team prior to starting the visits in each respective area. Carers who were identified for the visits were each sent a letter (see Appendix 3) advising them of the approach and with the option for opt out should they wish. Very few carers did opt out, with approximately 85% willing to think about future planning, to begin putting plans in place and in sharing information. Each of the 166 interviews was recorded to form the basis of this report. Informal feedback was gained from carers and from colleagues and in many cases, further follow-up work ensued. It could be argued that the success of action research can be measured by participants feeling empowered and energized, that clearer insight can be gained (Reason and Bradbury, 2006:344), however, whilst in some cases this will be true, by the nature of the caring role this will never be the case for some older carers who rather than feeling empowered, will always feel in need of some help or guidance, particularly if frail themselves and/or at the far end of the older age range. Semi-structured interviews were used essentially as a best fit for the topic and client group in the approach that South Lanarkshire Council wished to take. This allowed for some initial questions to be posed (through a range of open and closed questions) but interviews were very much steered by the carers and Social Workers in their discussions.

The purpose of the visits was to support older family carers in thinking about planning for the future (see Appendix 4). The semi-structured nature of the interviews was based on the concerns raised by carers in the initial research carried out for South Lanarkshire Council (Martin and Johnston, 2005) and so carers were ‘steered’ through the topic of legal provision for example and broadly chatted through the difficulties of passing away intestate, of the effect on benefits if money is not left in a Trust etc, of not necessarily having the legal right to make decisions for the person they provide care for. This topic allowed for carers to ask questions around their legal rights and to plan ahead in getting independent legal advice if desired (see Table 1). In terms of housing options, older family carers were able to explore options around where their relative might live in the future and what they might need to do to try and begin to secure this. Some older carers in particular did not appreciate the length of time it can take to secure housing through registered social landlords. Time to Think About... also discovered that some older carers believed their relative was on the ‘housing list’ when in fact they were not and so some assumptions were dispelled and acted upon through focussing on housing. The visits also addressed emergency planning (see Appendix 5) and highlighted that more work needs to be done in this area, with an informal reliance on family members for many. Older family carers were also made aware of their right to a Carer’s Assessment and of the support offered to carers within South
Lanarkshire. The visits also recorded carers’ health concerns with a view to shaping services. Questions were compiled as a result of the findings from Martin and Johnston’s report (2005) as stated and from reading many of the research papers published by The Foundation for People with Learning Disabilities to direct the shape of the interviews.

**Limitations**

Whilst this methodology lends itself well to encouraging carers to express their feelings and chat about their concerns, a clear limitation of course is in capturing and analysing very individual, subjective responses. Data were captured using a coding frame and emergent themes developed alongside very clear, emphatic responses from participants. Though 166 interviews were completed, on some occasions there was a single carer interviewed and in others, couples were interviewed. In the data analysis, feedback from carers is given as a percentage, some percentages are low and this is a consequence of the semi-structured nature of the responses (what was explicitly said by carers was recorded so actual figures could be higher).

**Evidence-based practice**

South Lanarkshire Council has set out to make research its ‘core business’ (South Lanarkshire Council, 2008) and Time to Think About… fits with the local authority’s wider strategic aims in encouraging evidence-based practice. The Social Worker, whilst overseeing Time to Think About… has identified ‘gaps’ in practice (through independent research and with carers and colleagues as well as with partner organisations) and set about trying to bridge some of these. In the last five years these developments have included:

- Researching and designing a resource pack to accompany Time to Think About…
- Setting up therapies for carers in their own localities
- Writing in the newsletter under ‘Learning Disability News for Carers’
- Researching and developing an ‘emergency planning tool’
- Promoting and completing Carers’ Assessments
- Increased year on year one-to-one support offered to carers (solution focussed).
- Future planning workshops organised each year for carers in their localities.
- Advising carers of their rights
- Chairing a strategic planning group for carers (Partnership in Practice)
- Researching housing models for adults with learning disabilities (carried out by the dedicated worker in the first few months of the post)
Colleagues from Housing and Technical Resources have worked closely with the dedicated worker in providing information to carers through the Carer Information Fayres, roadshows for carers organised by South Lanarkshire Carers Network, in contributing to the newsletter, in writing for the resource pack and in attending the Carers’ Partnership in Practice Group. Learning Disability Awareness Training was also developed by Housing and Technical Resources (with input from carers) from 2007 – 2009 and this was attended by almost 300 staff.

The evidence base for taking forward good practice in social work is multifaceted (Gordon and Cooper, 2010) from getting feedback at carers’ meetings, visiting other resources, speaking to colleagues, reading examples of good practice and using electronic research tools such as IDOX and SSKS (Social Services Knowledge Scotland) online. Supporting the principles of action research is using research to make a difference; keeping the outcomes for carers and service-users always in sight, but to work within a cycle of action and reflection as argued by Reason and Bradbury (2006:2). Action research should be of benefit to carers, it should be practical and may also be used by other agencies/colleagues so that the research ultimately influences practice three ways; for the researcher, the participants and for those with an active interest in the work.

**Ethics**

After identifying the carers to approach to chat through future planning, letters were sent to each of the carers (see Appendix 3) explaining the background to Time to Think About… that feedback from carers would be kept confidentially in service-users’ files and that the data collected would form the basis of a final report. At this stage, carers were given the opportunity to opt out of the visits with some telephoning the Social Worker leading the piece of work and others, when contacted to arrange the visit, opting out at that stage; the main reasons given that carers were either not ready to think about future planning or that it was not a convenient time for them. Carers therefore gave informed consent (Kalof, Dan and Dietz, 2008) in talking through future planning and each interview conducted was recorded in writing (see Appendix 4) and stored on file in line with The Data Protection Act 1998. In analysing the actual data (in working with The University of Dundee) all proformas were anonymised. Where further, follow-up work was needed after a visit such as approaching Housing and Technical Resources to check if a housing application had been made or in completing a benefits check, then in line with South Lanarkshire Council’s Sharing of Information Protocol, a consent form was completed by the carer as is usual practice. Respecting colleagues’ right to confidentiality in this piece of work can also be evidenced as their details were removed from the proformas submitted for analysis.

This approach to working with carers may be described as naturalistic, conducted very informally in carers’ own homes. This approach was taken deliberately with improving practice at the very heart of the research and even though carers were informed of the aims of Time to Think About… it could be argued that some carers would not have considered themselves
to be taking part in ‘research’ by the very nature of the informality of the interviews. Prior to each team beginning their interviews, colleagues were reminded of the sensitive nature of the topic in raising carers’ own mortality as a sub-text. Staff were asked to use their own judgement during conversations, ‘ethical guidelines insist that researchers should not do physical or psychological harm’ (Wisker, 2008:87) and a couple of colleagues did feedback that carers had found this difficult to talk about and so changed the angle of the interview. Prior to beginning the interviews (in briefing sessions with colleagues in the Adult Teams), the sensitivity of this piece of work was explored. Some carers did report that discussing future planning was a “difficult thing to do”, but as with a similar study completed recently in Australia, ‘concern of the parents/carers, about their person they care for, outweighed their distress and they realised that by participating in the process they were potentially making things easier for themselves and gaining peace of mind’ (Cartwright et al., 2008:xiii).

Whilst Time to Think About... is arguably an innovative approach in talking to older family carers, it must not be forgotten that discussing the lives of adults with learning disabilities is also at the heart of this. Discussion generally took place with service-users not present, for a number of reasons but not with a view to making decisions about adults with learning disabilities. Time to Think About... is an approach to supporting carers. It is in some ways the starting point of good practice and when information has been shared and questions answered (with the carer) the next stage is to begin to work with the carer and the person they provide care for in balancing both wishes for the future. This approach builds very much on the rights of service-users to make their own choices but is also taking into account carers’ rights in care planning. Service-users within South Lanarkshire are well supported through Speak Out Advocacy and The Advocacy Project to ensure their rights are upheld.
Data analysis

Legal issues

Carers were asked questions in relation to the legal arrangements made for the person they care for. Table 1 summarises the percentage of carers within each area that have attended to or are considering taking action with regard to important legal issues.

Table 1
Percentage of carers in each area considering legal options

<table>
<thead>
<tr>
<th></th>
<th>East Kilbride (n=47)</th>
<th>Larkhall (n=13)</th>
<th>Clydesdale (n=23)</th>
<th>Blantyre (n=39)</th>
<th>Hamilton (n=30)</th>
<th>Rutherglen and Cambuslang (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers who have DWP Appointeeship</td>
<td>36%</td>
<td>77%</td>
<td>74%</td>
<td>72%</td>
<td>70%</td>
<td>79%</td>
</tr>
<tr>
<td>Carers who have made a Will</td>
<td>46%</td>
<td>46%</td>
<td>43%</td>
<td>33%</td>
<td>23%</td>
<td>35%</td>
</tr>
<tr>
<td>Carers who have POA or Guardianship</td>
<td>13%</td>
<td>31%</td>
<td>17%</td>
<td>15%</td>
<td>13%</td>
<td>21%</td>
</tr>
<tr>
<td>Carers who have set up a Trust Fund</td>
<td>6%</td>
<td>0%</td>
<td>9%</td>
<td>8%</td>
<td>13%</td>
<td>0%</td>
</tr>
<tr>
<td>Carers now looking into POA or Guardianship</td>
<td>23%</td>
<td>46%</td>
<td>22%</td>
<td>8%</td>
<td>27%</td>
<td>57%</td>
</tr>
<tr>
<td>Carers now looking at setting up a Trust Fund</td>
<td>13%</td>
<td>8%</td>
<td>9%</td>
<td>0%</td>
<td>27%</td>
<td>14%</td>
</tr>
<tr>
<td>Carers now going to make a Will</td>
<td>17%</td>
<td>8%</td>
<td>0%</td>
<td>8%</td>
<td>30%</td>
<td>21%</td>
</tr>
</tbody>
</table>

Emergent themes

It is interesting to note that as a result of some of the visits, we have seen a proactive response from a good number of carers, who after individual discussion said that they would look into their legal rights and/or those of their sons and daughters. Carers who attend formal carers’ meetings were not always those who had put in place plans. Though many carers had made a Will, there were few Trust Funds in place to safeguard any monies that might be left and certainly there is an assumption amongst carers that carers (very often as next of kin) do have the right to make decisions for an adult son or daughter. It is clear from the high number of carers as DWP Appointees that the immediacy of handling day-to-day benefits has been addressed by many but arguably, longer term financial planning (as in making a Will for some) is still to be addressed.
**Housing**

The interviews broached the issue of the housing needs of the person with a learning disability if carers were no longer able to provide care through illness or death. Table 2 summarises the plans made across all six areas.

**Table 2**

**Percentage of carers in each area addressing housing options and support**

<table>
<thead>
<tr>
<th>Carers stating no plans are in place</th>
<th>East Kilbride (n=47)</th>
<th>Larkhall (n=13)</th>
<th>Clydesdale (n=23)</th>
<th>Blantyre (n=39)</th>
<th>Hamilton (n=30)</th>
<th>Rutherglen and Cambuslang (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>15%</td>
<td>15%</td>
<td>39%</td>
<td>3%</td>
<td>30%</td>
<td>43%</td>
<td></td>
</tr>
<tr>
<td>Carers stating a housing application will now be made</td>
<td>19%</td>
<td>8%</td>
<td>13%</td>
<td>8%</td>
<td>10%</td>
<td>36%</td>
</tr>
<tr>
<td>Carers stating a housing application is already in</td>
<td>21%</td>
<td>8%</td>
<td>4%</td>
<td>8%</td>
<td>16%</td>
<td>29%</td>
</tr>
<tr>
<td>Carers wanting their relative to remain in the family home</td>
<td>8%</td>
<td>38%</td>
<td>30%</td>
<td>38%</td>
<td>33%</td>
<td>43%</td>
</tr>
<tr>
<td>Need for 24 hour care identified</td>
<td>38%</td>
<td>38%</td>
<td>43%</td>
<td>38%</td>
<td>33%</td>
<td>43%</td>
</tr>
<tr>
<td>Family to provide 'hands on' care</td>
<td>6%</td>
<td>8%</td>
<td>4%</td>
<td>23%</td>
<td>10%</td>
<td>7%</td>
</tr>
<tr>
<td>Carers who said 24 hour care is not needed</td>
<td>44%</td>
<td>23%</td>
<td>22%</td>
<td>13%</td>
<td>7%</td>
<td>14%</td>
</tr>
</tbody>
</table>

**Emergent themes**

Individual carers gave a variety of answers when asked about their thoughts on where their son or daughter might live in the future, demonstrating a range of person-centred options is very much needed. The majority of carers now looking at their relative with a learning disability remaining in the family home supports the shift in policy away from thinking about residential care, though carers will often cite loneliness as a concern if people with learning disabilities are to live independently in the community but with support. Again, a proactive response was observed with some carers now beginning to address housing options with their son or daughter with a learning disability and
to physically putting a housing application in. Some carers very clearly state that they wish to continue providing ‘hands on’ care when their son or daughter moves out of the family home but for many carers they do not wish for other sons or daughters (siblings) to take on some elements of care provision. Carers are increasingly becoming aware of how a combination of technology and ‘hands on’ paid care can, for some, equate to 24 hour care though gaining families’ confidence with ‘new’ technology takes time, skilled risk assessment and monitoring to demonstrate this.

**Support**

Carers were invited to discuss a range of issues regarding their support needs as well as Carers’ Assessments. Table 3 summarises these results.

**Table 3**

**Percentage of carers in each area discussing their own support**

<table>
<thead>
<tr>
<th></th>
<th>East Kilbride (n=47)</th>
<th>Larkhall (n=13)</th>
<th>Clydesdale (n=23)</th>
<th>Blantyre (n=39)</th>
<th>Hamilton (n=30)</th>
<th>Rutherglen and Cambuslang (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers who are members of The Murray Owen Older Carers’ Group (MOOCG)</td>
<td>43%</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>N/A</td>
</tr>
<tr>
<td>Carers accessing other carers’ organisations</td>
<td>13%</td>
<td>15%</td>
<td>22%</td>
<td>8%</td>
<td>7%</td>
<td>43%</td>
</tr>
<tr>
<td>Carers stating they do not wish to access carers’ support</td>
<td>15%</td>
<td>23%</td>
<td>48%</td>
<td>44%</td>
<td>0%</td>
<td>29%</td>
</tr>
<tr>
<td>Carers supported by family members or friends</td>
<td>15%</td>
<td>8%</td>
<td>35%</td>
<td>23%</td>
<td>50%</td>
<td>14%</td>
</tr>
<tr>
<td>Carer’s Assessment taken up as part of Time to Think About…</td>
<td>5%</td>
<td>23%</td>
<td>17%</td>
<td>5%</td>
<td>17%</td>
<td>21%</td>
</tr>
<tr>
<td>Carer’s Assessment already completed</td>
<td>17%</td>
<td>31%</td>
<td>26%</td>
<td>23%</td>
<td>27%</td>
<td>21%</td>
</tr>
</tbody>
</table>
**Emergent themes**

Not surprisingly we have seen an increase in the number of Carers' Assessments taken up as a result of taking time to explore this as an option for carers and though nearly half of those carers questioned in East Kilbride were members of the campaigning group, The Murray Owen Older Carers' Group, it could be argued that attendance at the group does constitute support. Though some carers are also members of South Lanarkshire Carers Network (though a campaigning group), it could be argued that support is actually gained by those who attend the monthly carers' meetings. Some carers of course are members of carers’ organisations but receive little practical support. For some carers, knowing that the organisations are there, should they be needed is reassuring in itself. It is interesting to note how many carers said they were not interested in accessing formal carers’ support and many reasons exist for this. The relatively high number of carers accessing support in Rutherglen and Cambuslang when juxtaposed with other areas is attributable to many families’ historical involvement with the local ENABLE Scotland branch. There is a divide between carers who do look to family and friends for support and to those who feel they cannot look to the nuclear/extended family for emotional and practical support.
**Emergency planning**

Carers were invited to talk about what would happen to the person they care for in the event of an emergency. Table 4 reports on the percentage of carers who had made plans and the extent of those plans.

### Table 4

**Percentage of carers in each area addressing emergency planning**

<table>
<thead>
<tr>
<th></th>
<th>East Kilbride (n=47)</th>
<th>Larkhall (n=13)</th>
<th>Clydesdale (n=23)</th>
<th>Blantyre (n=39)</th>
<th>Hamilton (n=30)</th>
<th>Rutherglen and Cambuslang (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific consideration given to planning for an emergency</td>
<td>17%</td>
<td>0%</td>
<td>9%</td>
<td>5%</td>
<td>3%</td>
<td>21%</td>
</tr>
<tr>
<td>Carers stating family members would ‘step in’</td>
<td>47%</td>
<td>31%</td>
<td>30%</td>
<td>23%</td>
<td>20%</td>
<td>50%</td>
</tr>
<tr>
<td>Carers requesting care in the home should an emergency arise</td>
<td>13%</td>
<td>8%</td>
<td>13%</td>
<td>0%</td>
<td>10%</td>
<td>43%</td>
</tr>
<tr>
<td>Carers stating they would rely on Social Work Resources</td>
<td>11%</td>
<td>8%</td>
<td>13%</td>
<td>13%</td>
<td>17%</td>
<td>36%</td>
</tr>
<tr>
<td>Carers stating they will now think about emergency planning</td>
<td>9%</td>
<td>15%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>14%</td>
</tr>
</tbody>
</table>

**Emergent themes**

Emergency planning falls into two distinct categories for many carers: a reliance on family members and the knowledge that Social Work Resources will step in through the duty of care. What is very clear is that few plans are in place and that the uncertainty of what will actually happen when an emergency arises remains a concern. Minimising the effects of an emergency has been greeted with cautious optimism by older family carers within South Lanarkshire (those questioned), though there is scope for further exploratory work to be done here. Some carers were keen to stress that family members could be relied on in the short-term but concerns were also expressed about the lack of (or perceived lack of) traditional respite provision. Very few carers said they would now address emergency planning, perhaps because of the ‘safety net’ provided by the local authority or because no guarantees can be made. Working towards a person-centred response remains a priority in supporting carers and service-users.
Carers’ health
Carers were invited to talk about their own health status. Table 5 identifies the percentage of carers within each area describing their health status.

Table 5
Percentage of carers defining their own health status

<table>
<thead>
<tr>
<th>Carers stating their general health is ‘OK’</th>
<th>East Kilbride (n=47)</th>
<th>Larkhall (n=13)</th>
<th>Clydesdale (n=23)</th>
<th>Blantyre (n=39)</th>
<th>Hamilton (n=30)</th>
<th>Rutherglen and Cambuslang (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers stating their health is ‘good’</td>
<td>13%</td>
<td>8%</td>
<td>22%</td>
<td>10%</td>
<td>23%</td>
<td>29%</td>
</tr>
<tr>
<td>Carers with significant health problems</td>
<td>53%</td>
<td>31%</td>
<td>39%</td>
<td>28%</td>
<td>63%</td>
<td>43%</td>
</tr>
<tr>
<td>Carers with life-limiting conditions</td>
<td>9%</td>
<td>31%</td>
<td>9%</td>
<td>5%</td>
<td>13%</td>
<td>14%</td>
</tr>
<tr>
<td>Carers stating their emotional health is not good</td>
<td>9%</td>
<td>15%</td>
<td>22%</td>
<td>8%</td>
<td>23%</td>
<td>14%</td>
</tr>
</tbody>
</table>

Emergent themes
Given that much of the literature supports the argument that carers themselves often experience poor physical (and indeed emotional) health, findings from Time to Think About… are interesting in that many carers stated their health was ‘good’, though a significant number actually went onto say that they have health issues such as Osteo-arthritis, back pain etc. Responses are highly subjective and the interpretation of ‘emotional wellbeing’ varies considerably, for instance, a carer may say that her emotional health is ‘ok’ but goes onto say that she suppresses her emotions as she does not want to ‘burden’ her family, she may benefit from attending counselling, though may decline a referral because of what still remains a stigma in terms of accessing counselling and the ‘mental health’ label.
Rights / legal issues

All carers have a right to have their views taken into account when local authorities are determining how best to meet the care needs of a disabled person (Clements, 2011) and carers providing (or whom intend to provide) a substantial amount of care on a regular basis are also entitled to have their needs assessed under The Carers (Recognition of Services) Act 1995. The Health and Social Care (Scotland) Act 2002 placed a statutory duty on local authorities to inform carers of their right to an assessment and also gave Scottish ministers a power to direct NHS Boards to develop a Carer Information Strategy, which essentially set out to identify how NHS Boards would inform carers of their potential right to an assessment of need. It is encouraging to see from the data (Table 3) that through Time to Think About… the number of Carers’ Assessments completed did increase. This is arguably through taking the time to advise carers of their right to have their needs assessed. Whilst carers have gained recognition and new rights in the last fifteen years, many carers would argue that services still fall short of meeting their needs, (Yeandle, 2007) and it has been argued that the laws in place to support carers and uphold their rights are not widely known or applied (Robinson and Williams, 2002). Collectively, campaigning groups such as the Murray Owen Older Carers’ Group and Greensyde Carers’ Group in Renfrewshire have been, perhaps indirectly able to inform carers of adults with learning disabilities of their rights. However, it could be argued that older family carers of adults with learning disabilities who are not in touch with groups (and so consequently are not as well informed) are less likely to be aware of their legal rights. Certainly, within South Lanarkshire there has been a concerted effort to raise awareness amongst carers of adults with learning disabilities of their rights (see Tables 1 and 3) and through Time to Think About… older family carers have gained knowledge in relation to their rights, though only some have acted upon the knowledge gained. This is demonstrated in Table 1 for example where in East Kilbride 13% of carers had taken out Power of Attorney or Guardianship but just a further 23% stated they would now look at legal provision. Through Time to Think About… many older carers did report that they were not aware that they did not have the legal right to make decisions for their adult son or daughter. This awareness raising in terms of rights can also be evidenced through providing information workshops for carers of adults with learning disabilities covering such topics as legal rights, direct payments and housing options. Carers work with the Social Worker in developing ‘Learning Disability News for Carers’, which is a dedicated section in the newsletter provided by South Lanarkshire Carers Network. This reaches 600 carers of adults with learning disabilities across South Lanarkshire and covers areas such as changes in policy and legislation. It also seeks to reach ‘hidden carers’ through distribution within the health centres across the authority. The Social Worker has also seen an increase in the amount of carers she is supporting who will accept a Carer’s Assessment and this can be evidenced through her referrals (see also Table 3).
Accessing help

In the evaluation of The Moffat Project, Preventing Crisis for Carers, which ran across four NHS Board areas from 2008-2010 it was noted that dedicated carer support significantly increased the number of Carers’ Assessments offered, the number of Carers’ Assessments completed and that the process and outcomes of the assessment were viewed more positively by carers (Kelly et al., 2011). Providing carers with information to empower them, ultimately should be a multi-agency approach but arguably carers do benefit from dedicated support. Again, dedicated support can be evidenced through Time to Think About... (Tables 1, 2 and 3) demonstrating that one-to-one support can be effective and empowering; some carers went onto action things as a result of a dedicated response to their needs. Concerns remain though for older family carers who perhaps have little involvement with Social Work and who are not accessing any formal carers’ support. Carers of adults with learning disabilities talk of receiving information from other carers (Martin and Johnston, 2005) but also of the ‘fight’ for resources when trying to access help (Sardi, 2008, Kelly, 2007). Time to Think About... does challenge this negative view held by carers in terms of information though and again, from the tables showing the proactive response from some carers when provided with information (Tables 1, 2 and 3) we see that information provided directly by Social Workers has been acted upon. Some older carers still remain fearful of ‘rocking the boat’, they may be tired of fighting for services and having requests rejected, actually aware of their right to request help but fearful of presenting as unable to cope and concerned that the possibility still remains of their son or daughter being taken away from them (Hubert and Hollins, 2000).

Making provision

Service provision should be needs led (currently with a shift towards an outcome-focussed approach) though concerns are raised by older carers of adults with learning disabilities as to the ‘equity’ in terms of assessing need and allocating resources; older family carers relay concerns to the author of this. It has been argued that carers of adults with learning disabilities from BME backgrounds in particular are relatively disadvantaged when trying to access services (Hatton, et al., 1998) and that socio-economic factors play a part in determining the outcome for carers exercising their rights, that those from more affluent backgrounds are likely to receive more support (Hatton, et al., 1998). However, carers from BME backgrounds supporting an adult with a learning disability are also less likely to be in touch with services as argued by Hatton et al. This leads us to question though whether services are targeted to those most in need or whether they are disproportionately allocated; parallels can be drawn here with carers who are less vociferous than others (across the board); whether those older carers who really need the support are getting it. It was anticipated (prior to beginning Time to Think About...) that older family carers in East Kilbride would have been most prepared in terms of making legal provision (because of the Murray Owen Older Carers’ Group) but the data collated does not support this; carers in Larkhall had a higher percentage showing that they had
taken out Guardianship or been granted Power of Attorney. However, in East Kilbride and again in Larkhall, carers recorded the highest numbers in terms of making a Will and in all but one locality (again with East Kilbride as the exception), over a third of older family carers had taken DWP Appointeeship to manage their relative’s benefits. Feedback from the Hamilton visits suggests that older carers in this area were most likely to have set up a Trust Fund. These figures are interesting in that they demonstrate a very individualised approach to legal provision in terms of future planning. Though older carers may attend support/campaigning groups, they may not necessarily be those most prepared, though arguably they remain well informed. However, it is clear that through education/informing carers that this approach also leads carers to seek independent legal advice in relation to future planning (as we can see from the data); that some older carers have instigated this as a result of Time to Think About…, with carers in Hamilton taking the most proactive approach in making a Will. This also supports the argument that carers wish to be informed but are not seekers of information (Martin and Johnston, 2005). Figures for Blantyre are the lowest in terms of older carers now seeking independent legal advice. This area team covers a very diverse socio-economic demographic and reliance on family members remains fairly high in this area. It is also important to bear in mind that for many older carers the prospect of applying for Guardianship is a daunting one though and where there is little option of a joint Guardian, older carers are likely not to want to be able to pursue this because of the responsibilities it places on them. However, good legal planning can in some ways minimise the effects of a future crisis if decisions can be made by an appointed Guardian and older carers can feel empowered and reassured by having addressed such issues (even if this is merely in making a Will). Time to Think About… allowed older carers to chat through their plans and to amend them where necessary such as if carers disclosed they were leaving money to their son or daughter with a learning disability but Social Workers had then chatted about setting up a Trust Fund to safeguard benefits. For the numbers of carers who said they would go on to make a Will, the visits were perhaps a useful starting point in future planning. Much of the literature provided in relation to older carers (Martin and Johnston, 2005, Quarriers, 2008, ENABLE Scotland, 2008, Magrill, 2005) is supported by quotes from older carers feeling unsupported in making plans. Whilst ‘one off’ visits arguably cannot equate to ‘support’ they form the foundation for many older carers in beginning to address a very difficult issue.

**Shaping support for older carers: Legal issues**

- It is imperative that all older carers who provide a regular and substantial amount of care continue to be advised of their legal right to a Carer’s Assessment. This should be part of building a therapeutic relationship with the carer (or perhaps as part of the review process) and not offered at a time of crisis, with a clear outcomes focus for carers but in incorporating ‘planning’ (if the carer wishes) to lessen anxiety first and foremost.
• Carers’ organisations, NHS Lanarkshire and South Lanarkshire Council should continue to work in partnership in providing information to carers of their right to an assessment.

• South Lanarkshire Council could also review the current Carer’s Assessment form considering whether this is a suitable document to record the needs of an adult with a learning disability who is providing care to an older parent (as interdependency increases).

• Social Workers cannot provide legal advice of course and many only have a very broad understanding of Trust Funds, Guardianship etc but should discuss legal ‘options’ with family carers when appropriate to empower carers and minimise the effects of crisis.

• Legal rights/provision could be addressed as part of the review/Carer Assessment (built into the form). It is clear that carers welcome the chance to chat about legal options on a one-to-one basis (for many) rather than to attend workshops where they may feel inhibited in asking questions.

Housing

Arguably the biggest ‘problem’ facing older family carers of adults with learning disabilities in thinking about the future is two-fold – where the person will live and what support they will receive. There is a 30 year shortfall in meeting the housing demand for adults with learning disabilities (MENCAP, 2002) in the UK though this is not simply a Nationwide issue. America has also seen its population of adults with learning disabilities increase with services and housing demand outstripping supply. A study across 45 states concluded that 63,000 adults with a learning disability are on waiting lists for community based residential places (Davis, 1987 cited in Kelly and Kropf, 1995:5). MENCAP suggests that due to the sheer volume of adults with learning disabilities living longer that alternatives to the family home will need to be looked at (2002:6).

Whilst no-one would disagree that prioritising the long-stay hospital closure was the right thing to do, there remains a feeling (a perception) for some older carers of adults with learning disabilities (Clark, 2011, ENABLE Scotland 2008, MENCAP, 2002) that their sons or daughters still living in the family home have been ‘forgotten about’. This is exacerbated by the fact that, as stated previously only a quarter of these families are actually known to services (data retrieved from the 2011 Census should highlight to local authorities how many potential new ‘service-users’ may become known to them as older carers pass away before their sons or daughters for the first time in history). How has this perception of being forgotten about materialised? Certainly, the numbers of older carers supporting their son or daughter with a learning disability at home is evidence enough, and if anything, is likely to be underestimated. At a local level older carers hear of crisis driven situations where an older
carer passes away and no plans have been put in place. The reduction in local authority housing stock adds to the problem and changes in the Social Worker’s role (to one of minimal intervention) can leave older carers feeling very alone. It is extremely difficult to ascertain the extent of the problem and to start to break it down bit by bit as it is so multifaceted. The problem is not simply that there is not enough housing to meet the demand as perceived by older carers but this remains a perception all the same.

This is evidenced through some older carers telling the dedicated worker that they are ‘waiting’ for supported accommodation for their sons and daughters, through older carers waiting for suitable local authority housing stock to become available in a ‘good’ area and through Social Workers reiterating that service-users are on ‘the waiting list’ for housing. Predicting housing demand for adults with learning disabilities is complex as plans change periodically. Other issues have come light through the course of the Time to Think About… visits:

- A very varied response to meeting housing needs is required which can be evidenced from the data. There are more older carers wanting to support their son or daughter within the family home than perhaps first thought with just over a third of carers stating this is their wish (it would be useful for Social Work Resources and Housing and Technical Resources to compare this figure with the findings of the 2005 report in influencing future planning). The figure of just 8% in East Kilbride contrasts sharply with other localities and this may be attributable to the work of The Murray Owen Older Carers’ Group in some respects. Though older family carers may state they wish for their son or daughter to remain in the family home, they may not be aware of the difficulty in securing funding for 24 hour care packages if needed. Some older carers said that other family members would provide an element of care, with Blantyre having the largest figure of 23% here.

- From informal feedback given to the author from some older family carers, there does remain a demand for small scale group homes (similar to a sheltered housing model but on a smaller scale) and/or the core and cluster model, which older carers perceive as being ‘safe’ (geographically because a person with a learning disability is not living on their own in the community, care is provided over a 24 hour period and socially, adults with learning disabilities are not isolated by living on their own in the wider community) but this demand is not as high as first thought and the findings in this report conclude that a varied response is wanted by carers. Carers did not discuss in great detail what type of housing model would best suit their son or daughter and one of the reasons for this is that perhaps they look to the Social Worker to inform them of what is available (ENABLE Scotland, 2008, MENCAP, 2002) but what does remain a concern is the level of adults with learning disabilities recorded as requiring 24 hour support with figures averaging almost 40%. Securing this level of support within the family home is predictably going to be more
and more difficult to achieve (particularly as ILF applications have ceased) and more people with profound and multiple learning disabilities (PMLD) are now living longer, healthier lives. Whilst this of course can be celebrated, it remains a concern for families how care packages will be met.

- Several older carers stated that it is their wish to look at a familial model of housing or support for their son or daughter. Some options discussed were for another sibling to move into the family home to provide an element of care, or for an extension to be made to the family home with the intention of the service-user remaining there and some plans were already underway. This very much takes on a partnership approach with the local authority where the longer term vision would be to part fund a significant care package. This approach fits well with the concept of ‘personalisation’ and could, in theory, work for many families. However, circumstances change, family relationships are malleable and it is not clear from the data how many carers had firmly put in place these plans with other sons or daughters.

- A consideration for older carers thinking about housing options is centred very much around the level and crucially the quality of care to be provided for their son or daughter. This is of particular concern for carers supporting a person with PMLD, where a significant and often highly specialised level of care is needed (Morrison, 2011). Carers were not asked directly about their feelings towards the quality of paid care their relative may receive in the future, but concerns have been expressed to the dedicated Social Worker through carers’ groups within South Lanarkshire and through the Time to Think About... interviews as to the level of paid care that adults with learning disabilities may receive when supported to live ‘independently’. Carers need to know that the skills required to support their son or daughter are out there, that paid carers can provide the ‘expert’ level of care they do and consequently gain confidence in the social care workforce. These now ageing carers in particular may look to a familial model where possible or a more personalised approach which may take years to put in place; the emphasis on thorough planning early on is obvious. Some older carers supporting a person with PMLD who wish for their son or daughter to remain in the family home are, when thinking about future planning, beginning to look at Guardianship as a way of safeguarding their wishes. However, the data collated illustrates that only a few carers are looking at this, for example the percentage of carers requesting 24 hour care was much higher than those who stated they had Guardianship. What is significant is the number of carers looking to gain information on Guardianship or POA or to think about applying for this as a result of the visits though.

- For a significant number of older family carers, as discussed, the preferred option was for their son or daughter to remain in the family home. Davys and Haigh (2007) in their small scale
study also put forward this argument on behalf of families they interviewed. This option often relies on other family members to provide a level of care in the future but does not change things immediately for older carers reluctant to ‘let go’. It might simply be the easiest and less ‘threatening’ option for now. For older carers and for the person with a learning disability the desire to remain in the family home may simply be a continuation of family life, this might be what both parties want but it is important to determine whether this is their choice (both that of the carer and the person they provide care for) or simply their perceived only option (Hubert and Hollins, 2000). In a recent study of older carers carried out in Northern Ireland (Dillenburger and McKerr, 2010), only 72% of those interviewed had made ‘plans’ but again examples cited illustrate that family members will be involved in providing some element of care. When families talk of planning, plans are often informal but at least ‘the future’ has been discussed.

• Certainly from the high level of carers wishing to engage in Time to Think About… we can draw the conclusion that older carers do want to think about making plans with the intention of avoiding a crisis. There is, as stated a perception that securing housing, nationally, is often crisis driven, ‘local authorities rarely plan non-crisis moves because eligibility criteria give a low priority to non-urgent cases. People with elderly parents in their 70s or 80s are not regarded as a sufficient priority for arranging alternative housing provision, (MENCAP: 2002:7). This highlights for many, the real cause of the problem as it is perceived and leads us to question, is it really that housing and funding is so limited or is it that planned well enough in advance, needs could be met? If local authorities were to start working now with families to start planning, could crisis intervention later down the line be reduced?

• A small number of older carers stated that it was their wish for the person they provide care for to move into a nursing home (this term was used) and the reasons given were varied. Some older carers interviewed were in their late 80s/early 90’s with sons or daughters into their 60’s or 70’s with significant health needs. A recent report suggests that adults with learning disabilities across Scotland are being placed, often inappropriately in care homes for older people (Learning Disability Alliance Scotland, 2010c) and naturally challenges the ideology of The Same as You? Interestingly, the report highlights that where an Advocate was involved in supporting a person with a learning disability no-one was placed in a residential care home for older people (2010c:21). The report does also state that very few admissions were ‘crisis driven’ (a concern for many older carers) though and so arguably leads us to conclude that local authorities are endeavouring to meet needs in a person-centred way at a point of crisis.

• From the data collected just under a fifth of carers stated they had either put their relative’s name on South Lanarkshire Council’s housing list or that they were going to do so as a result of the
Time to Think About… visit. The amount of carers taking this proactive approach is encouraging and supports the argument that carers do wish to plan ahead. South Lanarkshire's Common Housing Register (CHR) now opens up options for carers to apply to registered social landlords and so increases the options available for carers and adults with learning disabilities. There are examples of good practice when looking at meeting housing needs such as the housing strategies specifically developed for adults with learning disabilities by some local authorities such as at Southampton City Council (Southampton City Council 2010), Newcastle, Worcestershire etc, and in Sheffield where older family carers’ needs can be taken into account when allocating housing points (Sharing Caring Project, 2010). Hammersmith and Fulham Housing Department is cited as having a Housing Officer for people with learning disabilities. South Lanarkshire Council’s Housing and Technical Resources involved carers in the consultation process when drafting the Housing Allocation Policy and in developing the new Local Housing Strategy and as stated, service-users and carers now benefit from the Common Housing Register within South Lanarkshire. However, some carers still state that they do not know what the housing options are (across all housing sectors). In terms of supported accommodation they do not know what is a possibility within their own area or surrounding areas and so cannot make informed choices. There is also a perception that when a housing application form is completed that carers then wait for a place to come up that may be suitable for their son or daughter. That is fine if older carers are planning ahead and can wait, but for those where the situation is more pressing older carers then need some support in moving things along.
Shaping support for older carers: Housing

The financial challenges of meeting the housing needs of adults with learning disabilities and of funding care packages is not going to go away. Ignoring this, at a national and a local level is not an option. From the data collated and emergent themes, the following issues have materialised:

The two departments of Social Work Resources and Housing and Technical Resources within South Lanarkshire Council should continue their good joint working in developing and taking forward an ‘action plan’ based on the findings from this report. An example of the success of working in partnership can be evidenced through the joint protocol agreed in April 2011 for adults lacking mental capacity in securing, maintaining and terminating their tenancies. Meeting the housing needs of adults with learning disabilities and their older carers was highlighted for the first time in Caring Together as a concern that needs to be addressed now, however, meeting the housing needs of other client groups is of course of equal importance. Working with families more thoroughly to plan for their individual housing needs may help to reduce older carers’ anxiety. Respecting service-users’ wishes for future housing remains at the heart of good practice as previously stated but in taking into account the health and social care needs of ageing parents.

Do older carers know of what housing options are available in their areas and how to access these (supported accommodation and through applying to South Lanarkshire Council)? Some carers are telling us that the answer is ‘no’. This is an area of practice that remains to be addressed and was originally highlighted in Martin and Johnston’s report (2005).

South Lanarkshire Council could consider taking into account older carers’ health and social care needs when awarding points for housing. This has previously been discussed but quantifying the numbers and determining the criteria for such a specific approach is still a matter that would benefit from further discussion. The local authority currently takes into account the medical needs of the service-user when other issues within the family are actually bringing about the pressing need to secure housing (such as the failing health of an older carer). The difficulty here of course is in prioritising the needs of one carer/client group over another. However, arguably this group of older carers are now, for the first time in a generation needing a targeted level of ‘housing support’.

Do older carers ‘slip through the net’ if there is no allocated Social Worker to help push forward a housing application? This may be happening in practice. Time to Think About... discovered that some older carers believed their son or daughter’s name had been on the housing list for years and when looked into, this was not the case.

South Lanarkshire Council could consider incorporating a future housing planning meeting as part of the Social Work review process for adults with learning disabilities and older carers (automatically when carers turn 50). This responsibility would lie within the remit of Social Workers, to thoroughly check that all available housing options have been opened.
up to families and all options explored. Carers often state that a housing application “has been in for years” but circumstances may have changed, new geographical areas could be opened up, some were put in with no medical points, ‘care and support’ points could now be awarded. Other registered social landlords could be applied to to open up other options. An open discussion about future housing and care needs should be built into a review process that is not a one-off piece of work, but cyclical.

Arguably, further training is needed for Social Workers in terms of maximising the options for older carers. This is evidenced by some colleagues unaware of the 60 points that can be awarded for ‘care and support’ for example if a person with a learning disability moves close to a family member or friend who is able to provide some support. This can of course move a housing application on. A meeting with a Housing Assistant/Officer is another option to look at progressing things and should be offered if an older carer and the service-user are keen to progress things.

Martin and Johnston, in their 2005 report recommended that Housing and Technical Resources and Social Work Resources should work together in recording and interpreting data, so as to, ‘anticipate need and respond effectively’ - quantifying the need and agreeing a joint approach would build on the successful joint working already underway (2005:25). Solely within Social Work Resources, Team Leaders rely on Social Workers to bring to their attention a request for 24 hour care (supported accommodation). If a Social Worker highlights this need and then ‘closes’ the case, how are the needs of the older carer met in ‘pushing’ for suitable housing to be offered though? A robust and consistent approach to securing supported accommodation could arguably be explored further.

Some older family carers may submit an annual form to South Lanarkshire Council (re-registration) stating that they wish for the housing application to remain ‘open’ and that no changes need to be made to the form. However, we are aware that older carers often underplay the state of their health (Dillenburger and McKerr, 2010) and so simply submitting a return each year may not in itself be enough to give a true picture of their needs. Completing this form could be part of an older carer’s ‘review’ (as mentioned in number 5).

Older carers continue to say that they are unaware of all the other options in relation to housing (outside of renting from the local authority). Despite efforts, the research data suggests that very few carers appear to know what the options are. For example, some older carers will assume that completing a housing application form through South Lanarkshire Council is sufficient enough; they may be unaware of the added option of applying to other social landlords who are not part of the Common Housing Register. Further awareness raising could be addressed in light of this report. They may be unaware of shared ownership options, the options of the family ‘buying to let’ etc.

Would it be beneficial to look at other housing models for the future, not only in terms of economy but to reassure carers that all options are being
looked at? This could be addressed jointly by Social Work Resources and Housing and Technical Resources in agreeing an ‘action plan’ to take forward together.

Whilst older carers’ needs have clearly been given priority in this section this in no way supersedes a service-user’s rights and choices in determining housing. There are two key recommendations to emerge from exploring the housing issues facing older family carers and adults with learning disabilities:

- That the specific issues highlighted in this report are jointly addressed by Social Work Resources and Housing and Technical Resources. This could be built into the existing Partnership in Practice Agreement (strategic planning for adults with a learning disability and their carers).

- South Lanarkshire Council should use this report as a starting point in predicting future demand for care and accommodation. This piece of work could be carried out through existing resources (from within the local office teams within Social Work Resources) but overseen by one staff member to co-ordinate this. It should be calculated on the basis of the numbers of children born with additional support needs as well as calculating the numbers of adults requiring care (currently dependent on family carers). This would give a reasonably accurate prediction for future provision.

**What is Support?**

It is clear from the data collated that older family carers of adults with learning disabilities source support in a range of different ways, through using coping mechanisms, family, friends, formal carers’ support (such as through The Princess Royal Trust Lanarkshire Carers Centre hereafter, PRTLCC or through South Lanarkshire Carers Network, hereafter SLCN). Older family carers within South Lanarkshire also benefit from specialist knowledge and support through The Community Learning Disability Team and organisations such as PAMIS (Promoting a More Inclusive Society) as well as through the support offered by South Lanarkshire Council, an obvious source of support being respite. South Lanarkshire Council took the decision to develop a specific post in relation to supporting older family carers and this good practice has been highlighted nationally (Charter for Change, 2010a) where calls for a dedicated post in each local authority were presented to the Scottish Government. Dumfries and Galloway now have a dedicated post for carers with a Social Worker recently employed by the local authority. There is mounting evidence in favour of supporting older carers and again, in England, numerous examples can be given of targeted support for this carer group, with Sheffield’s Sharing Caring Project leading the way. In Scotland, The Edinburgh Development Group (EDG) has developed its work around identifying and supporting older family carers, Renfrewshire now has a local authority post specific to the needs of older carers as well as dedicated staff within the Princess Royal Trust there to
support carers with emergency planning (although they are not learning disability specific posts) and ENABLE Scotland has developed older family carer support in Dumfries and Galloway and Ayrshire. It is still not clear what the picture is nationally through in terms of support for this carer group.

**Carer-centred support**

Is specific support really needed though and if so, why? Informal feedback from colleagues and carers regarding Time to Think About… was that the approach was beneficial, carers reported not having had the chance previously to have chatted so “in depth” about future planning but colleagues were also keen to highlight that we should be careful not to raise carers’ expectations. The comments in relation to raising expectations are in relation to funding care packages to support ‘independent living’ and in relation to a flat or house being offered. Social Workers are aware that for some older family carers, they feel unable to ‘wait’. This is evidenced through the individual referrals made to the Social Worker in this dedicated post and through feedback from some carers within South Lanarkshire. ‘One off’ visits to chat through future planning can certainly come under the ‘umbrella’ of support but does not constitute the on-going support older carers are sometimes seeking (we know this through older carers critical of not having an allocated Social Worker in some cases), which leads us to believe there is scope for looking at how we do offer support. Older family carers of adults with learning disabilities are unique as a carer group in many ways but do also, as stated share much in common with other carers and through Time to Think About… it may be possible to replicate good practice with other carer groups. The Social Worker overseeing Time to Think About… has seen an increase in referrals to work with older carers, some as a result of this process where she is approached by staff, partner agencies and carers. Time to Think About… visits resulted in many follow-up pieces of work, some undertaken by the Social Workers completing the visits and some by the Social Worker overseeing the work. In 2010 she received 40 new referrals; referrals have increased each year and the post is not promoted widely because of the limitations with one worker involved in a range of tasks (strategic and operational). If the post were widely promoted this would likely result in an increase in referrals. Though some older family carers of adults with learning disabilities are members of SLCN or are supported by the PRTLCC, those referred to the Social Worker are often in need of intensive, ‘carer-centred’ support. Carer-centred support is exactly as it sounds. In assessing need we talk of a person-centred approach but of practicing holistically, taking into account the needs of the carer. A carer-centred approach arguably works the other way round; the focus of the approach is the carer but not at the detriment of supporting the service-user. Having a sound value base is essential for this approach and to be able to balance the carer’s and the service-user’s rights. Her approach starts by questioning what the issues are for the carer. Common examples are: information on future planning, fear of thinking about the future, negotiating the housing system, carers unaware of support options and their rights and in a few examples there
may be communication problems; sometimes things need to be explained clearly to older carers to lessen anxiety. In breaking down what the carer needs help with, a process begins which is often time limited (working with the carer in supporting them with the initial ‘problem’ until achieving an outcome). The outcome is not always the desired outcome and where some things are not possible, good communication, (the approach taken) can make a difference in how the carer reacts. Through building up a therapeutic relationship with the carer and through keeping up communication at a time of intensive support being needed, this brings about a relationship of trust and mutual respect. This carer-centred, intensive support is multifarious, like the ‘support’ itself. If a carer needs to move things along in terms of housing for example, the Social Worker will arrange a meeting, constantly liaise with a Housing Officer, check that all housing options are opened up and not conclude the work until a house is offered. This is one example of tenacious, carer-centred support but in working with colleagues, service-users and advocacy partners. Carer-centred support can be time consuming but is undoubtedly carried out by Social Workers in their day-to-day practice, the main difference being though that Social Workers will offer support to the service-users and carers allocated to them. Service-users and their carers who are in South Lanarkshire Council’s Care Co-ordination System are not in regular contact with a Social Worker. Older carers in particular can feel “cast adrift” because of this.

McNeill at al., (2005) cited in Changing Lives Report of the 21st Century Social Work Review suggests that there are specific consistent components that lead to successful interventions with older people and this of course can be applied to supporting older carers:

- Accurate empathy, respect and warmth
- Therapeutic genuineness
- Establishing a therapeutic relationship or working alliance (mutual understanding and agreement about the nature and purpose of intervention).
- An approach that is person-centred, or collaborative and client driven
  (Scottish Executive, 2006:27)

Whilst most Social Workers would support this argument, their role in supporting carers as it stands is arguably a difficult one. For Social Workers building up a therapeutic relationship with the carer can be difficult because of conflicting demands, the Social Worker may have to explain that needs assessed cannot be met, that families will be charged for services etc and though dealing with difficult situations is part of the role, it arguably hinders building a rapport with carers. Discussing finances, specifically with older people can be seen as intrusive and may certainly be a barrier in building up a rapport (Manthorpe et al., 2007). Older family carers do know the person they have lived with all their lives, ‘best’ but they do not always know what is best for service-users and we know this because some carers are subject to Adult Support and Protection procedures.
The ‘system’
Social Workers are juggling conflicting demands within the context of holistic assessments and so remaining carer focussed as well as person-centred is difficult. Workers often say they feel caught in the middle and family carers often feel that they are being isolated or judged as being deliberately obstructive, ‘When ‘conflict’ is unpicked, many find that people are just coming at issues from different perspectives and things have been blown out of proportion and are relatively simple to resolve’, (Magrill, Sanderson and Short, 2005:15). Undoubtedly, a strength of this dedicated post is that the Social Worker is employed by South Lanarkshire Council, she knows the Social Workers, Team Leaders, Senior Managers, has access to assessments, can view case notes etc, she is in the very system that carers find hard to negotiate. Conversely, being in the system, she cannot advocate independently for carers and so draws on a range of skills in negotiating, offering support, linking into the two carers’ organisations, advocacy agencies and partner organisations where appropriate. The knowledge of resources both within the Council and within the wider authority inform her practice. Crucially though, through the post, support offered to older family carers aims to be carer-centred.

Formal support
The ageing process can significantly limit an older carer’s ability to manage as they once did; their personal coping mechanisms may lessen and social supports may also decrease as older friends and family pass away and children move on (Kropf and Greene, 1993). Almost a third of the carers interviewed though stated they seek support from family and friends, which supports the argument of looking to within the family for future supports. Arguably, younger carers (in their 50s) can still rely on family and friends; carers at the older end of the spectrum may struggle to source familial support as argued by Kropf and Greene. It is interesting to note that though nearly a third of carers stated they would look to the family and/or friends to offer support, a similar figure, averaging 30% would rely on them in an emergency. This suggests that for the short-term, carers assume family members or friends will ‘step in’, that older carers are perhaps unaware of the formal support that can be offered in an emergency or conversely some will be against the use of a care home in the short-term. It also suggests that a dichotomy exists as several older carers are not keen to have other family members take on the responsibility for providing long-term care; this was evidenced through emergent themes. Interestingly in Blantyre and Clydesdale, nearly half of the carers interviewed stated they were not interested in accessing formal carers’ support. There are many reasons why older carers do not wish to tap into support offered by carers’ organisations:

- Carers are unaware of the range of services offered
- There is a perception that only support groups are run
- Some of the feedback from carers of adults with learning disabilities reported that carers’ organisations cannot offer them the individual approach they are seeking at a time of difficulty
There is no ‘one size fits all’ in terms of carer support but for some older carers who tap into formal support this can work really well. Agencies offer a range of services to support carers generally and do so very well. However, Caring Together also highlights the need for a personalised response, ‘Carers, whatever their caring situation, require similar types of support but personalised to the caring situation and responsive to particular needs and individual circumstances,’ (2010:26). It is also important though to bear in mind that many carers simply wish to look to within the family for any help and will never choose to access formal carers’ support. The difficulty of course for the carers’ organisations, supporting such large numbers is that they simply could not offer such an intensive, individual approach to every older carer needing help and neither can one individual worker. When older carers present as needing help, this is often because a particular problem has arisen, often this is something practical and they will welcome someone, on an individual level to help them work through it. This kind of support can be likened to that given by an Advocate who may offer intensive, individual work that is time limited but with a goal in sight. Advocacy for carers is to be addressed as part of the Scottish Government’s Carers’ Strategy (Caring Together, 2010) and as part of South Lanarkshire Council’s Carers’ Strategy (South Lanarkshire Council, 2010). It is this very approach though (individual and practical but with a counselling skills approach that would benefit older carers) that older carers undoubtedly favour (Martin and Johnston, 2005, Wildman, 2010, ENABLE Scotland, 2008, Magrill, Sanderson and Short, 2005). This is what makes the current dedicated post within South Lanarkshire perhaps a success but leads us to question its sustainability and to look at the Council’s wider approach in supporting older carers.

Shaping support for older carers: Practice implications

Work with older family carers is an area of carer support that is arguably viewed as specialised, however, ‘There is a real danger that older families will remain marginalised if their needs and new work is not linked into mainstream services and strategies across service areas and across organisations. Workers across a whole range of settings need to be made aware of the needs of older families and able to point them in the right direction’, (Magrill, 2005:85). There are as many arguments for a case for a specialised post as there are against and this needs further exploration. The challenges of change are perhaps as follows:

1. South Lanarkshire Council could review the current model used in offering support to carers to encompass the very specific needs of older carers as highlighted in this report. This would also bring about change for carers supporting service-users from other carer groups. It would ultimately reduce the need for a specialised post if changes to practice resulted as an outcome. Older carers in Edinburgh recently questioned, cited two key strengths to the dedicated support offered to them through the Supporting Older Families Initiative: an action based approach (solution focussed)
through home visits and representation at a strategic level (Wildman, 2010). Staff were able to offer direct practical support and this intensive support was highly valued by older carers.

2. Renfrewshire can be cited as an example of good practice in supporting carers through having qualified Counsellors and trained Advocates offering support to carers. The latter is something currently being considered by some local authorities as part of their carer strategies including South Lanarkshire (Glasgow City Council, 2008, North Lanarkshire Council, 2009). These core skills are crucial in providing direct carer support but whether specific qualifications are needed (or simply some training for Social Workers in advocacy and a counselling skills approach) remains at the heart of the practice debate in working with carers.

3. South Lanarkshire Council could consider continuing the specific post in supporting older carers, which can be likened to North Lanarkshire Council’s, CLASP (Carer Liaison and Support Project) which is internally run and like the dedicated post with South Lanarkshire, benefits from this.

4. The local authority could develop an Older Carers’ Strategy and begin to look at the issues raised in this report through creating a strategic post (Carer Co-ordinator, as in post at Walsall Council for example) from existing resources to address the issues of:
   - Training for staff and partner agencies
   - Information for older carers
   - Recording
   - Working across both Older Peoples and Adult Services
   - Future planning
   - Emergency planning
   - Research
   - Personalisation approach with older family carers
   - Preventative intervention
   - Housing issues
   - Systems work e.g. carer protocols, assessment forms multi-agency working...

5. There is also the option of recruiting volunteers to provide direct 1:1 casework with older family carers. This would mirror the support offered by the Sharing Caring Project in Sheffield in many ways overseen by a paid Co-ordinator but staffed voluntarily. It would ease the workload of one staff member at present but would be cost effective.

6. South Lanarkshire Council could further research and develop a toolkit for working with older family carers to standardise and improve practice with this carer group. This would take some time to complete but could be done within existing resources and would build on many of the issues raised in this report.
As identified by Kelly (2007) carers actually need support on two levels: practical and emotional and both can be achieved through skilled, trained and qualified staff in advocacy and counselling who need to be tenacious and carer-centred. This approach is not learning disability specific.

**Emergency planning**

The need to address emergency planning for older carers is supported by the data collected through Time to Think About... and also through the literature (Supporting Older Families Initiative, 2009, Magrill, 2005, Martin and Johnston, 2005, ENABLE Scotland, 2008). Caring Together highlights the need to look at emergency planning (Scottish Government, 2010a) as does South Lanarkshire Council’s Carers’ Strategy (South Lanarkshire Council, 2010). For older family carers, what might happen in an emergency is of great concern, not least because social networks may have fallen away that were once there but emergency planning can again, benefit carers across the board, including young carers. It is with this vision that South Lanarkshire Council has developed an Emergency Planning Form (still in draft, see Appendix 5). This is an excellent example of using action research to bring about change through a process of diagnosing, planning action, taking action and evaluating (Coghlan and Brannick, 2007). Time to Think About... illustrates that several older family carers have given some thought to dealing with an emergency, which is supported by ENABLE Scotland's report (2008). Addressing emergency planning with carers has only recently been highlighted nationally (Caring Together, 2010) and some older carers will report having given this little thought, however, it is hard to imagine that this is never far from the subconscious. Emergency Planning is of course very difficult to do because no guarantees can be made as to what will happen in an emergency. A 'cushions model' (Magrill, 2005) is arguably the best way to try and lessen the impact of an emergency. However, this is the first of two parts in emergency planning and does not mean that firmer plans (the second part) should not be developed as an example of good practice. Working with older carers in trying to lessen the impact of an emergency needs a two-fold approach, sitting down with the carer (and where possible the service-user) to complete the form which should be as brief as possible. This also needs a consistent, strategic approach behind it within the local authority and ideally with the NHS as a partner. Addressing the complex health needs of some service-users in an emergency may cause carers a great deal of anxiety and this would need a joint approach to emergency planning. The Supporting Older Families Initiative (SOFI), based within the Edinburgh Development Group has been working with families to develop a Life Book, which is stored on the Social Work Department's database so that in the event of an emergency, there is a greater chance of a person-centred response (Wildman, 2010). Consideration also needs to be given to the approach taken, particularly with older carers who may be faced with confronting issues of ill health and their own mortality (Magrill, 2005). Work carried out in the voluntary sector around emergency planning such as through SOFI and
Renfrewshire Princess Royal Trust Older Carers’ Project has been at the forefront of good practice though in supporting a small minority, the challenge is to build on the good practice underway at a wider level.

The options in an emergency for older carers are in reality, few and this may be the reason, as stated that carers would look to family members in the main to provide support. An average of just 5% of carers said they would now sit down with family members to discuss emergency planning and only an average of 10% stated some thought had been given to emergency planning with the majority of carers relying on the Social Work Department or family and friends to cover an emergency. It has been argued that carers fall into two distinct categories of avoiders and planners (Seltzer and Krauss cited in Janicki, 2003) but certainly when prompted to think about emergency situations, it appears that older carers have considered options, albeit ‘plans’ are very loose. This preventative approach in drafting a form to work through with older carers not only offers ‘support’ on a practical level but on an emotional level too for carers. It is also a tangible outcome in shaping support for carers. The effects on carers’ health have been much documented (Yeandle et al., 2007, Carers Scotland, 2011a, Kelly, 2007) and certainly an aim of emergency planning is to reduce anxiety for carers (older carers in particular). Older carers should feel empowered by this approach with their needs at the very heart of this (but again, not to exclude the needs of the service-user). In a study carried out by Simpson (1997) of carers supporting a person with dementia, she concludes that working with carers as equals (in gathering information) is highly effective; that carers feel valued when professionals take the time to work with them in this way when information is jointly held. Though her study relates to carer held documents on the person with dementia, this document was centrally held by the carer with only certain professionals having access - this is the aim of the Emergency Planning Form. South Lanarkshire Council would hold, electronically the information put forward on the form by the carer so that it is carer-led and there would be no duplication in information needed.

**Knowledge**

Emergency planning is a contentious issue for some older carers who have witnessed a reduction in emergency ‘beds’ (respite places) and many carers are aware that a Duty Social Worker would essentially be the first point of call in an emergency (should there not be the ‘back up’ from family members). This heightens carers’ anxiety when thinking about an emergency and may also be another reason that looking to close family members in the short-term is the preferred option; they are also likely to know the person with a learning disability much better than a Duty Social Worker would in many instances. Just over 10% of carers had given some thought to extra support being put into the family home in case of an emergency and some carers (through emergent themes in the data) held very strong views that their son or daughter was not to be placed in a nursing home as a temporary measure.
Shaping support for older carers: in emergency planning

ENABLE Scotland has been granted funding by the Scottish Government for a two year project, to identify ways in which emergency planning can be developed effectively via Carers’ Assessments (ENABLE Scotland, 2010:1) and South Lanarkshire Council has been approached to be part of the Steering Group as their work in this area has been cited as an example of good practice.

The Emergency Planning Form has been presented to carers’ groups within South Lanarkshire and to Social Workers across the ‘Adult’ teams to gain feedback. It now needs to be decided where this will fit into ‘Assessment and Care Management’ procedures (in electronic format) before the form can be piloted with carers. Discussion should also take place with NHS partners as to the joint working approach before the form can be ‘signed off’ as a completed piece of work. Minimising the effects of an ‘emergency’ for carers through developing a tool/form may result in reduced anxiety for some, though alone would not hold enough information and further work could be undertaken in this area as to whether more detailed information could be drafted to accompany any form such as a Life Plan.

There is further scope to explore how we can practically ameliorate practice in working with older carers preventatively, to lessen the impact of an emergency. Different models exist essentially around future planning but incorporating emergency situations such as Shared Lives and circles of support co-ordinated by Equal Futures. For both models direct payments can be used and both models, though vastly different in their approach ultimately aim for a personalised, person-centred approach of benefit not only to the service-user but the older carer too. The difficulty with preventative approaches can often be the need to commit resources at the outset but in the knowledge that this is ‘spending to save’. Equal Futures uses a Canadian model of facilitating a ‘circle of support’ for service-users in which individuals (and organisations) can agree to offer practical support at given times including in an emergency. Shared Lives (with currently 36 schemes operating in Scotland) may in its simplest form be compared to fostering but the model is aimed at adults who may go and stay with families for respite or who may live with families in some situations, offering a personalised approach with proven, economic savings when compared to traditional forms of respite. This can average savings of £995 a week for people with learning disabilities in a Shared Lives placement compared to conventional supported living, (NAAPS, 2009:21). The Shared Lives model though favourably received by older family carers of adults with learning disabilities within South Lanarkshire may also be used across all other client groups. There is potential here to improve practice but save money at a relatively low price to deliver high quality, personalised support. If, through Self-directed Support there is the possibility of carers being awarded money (direct payments) in their own right, the option could be explored of giving carers money for an emergency – if it is not spent the money remains within the local authority budget.
Older family carers and carers’ assessments

Through Time to Think About… an average of 11% of older carers accepted the offer of a Carer’s Assessment. Though this is a relatively low percentage, the take-up of Carers’ Assessments across Scotland remains low. It is interesting to note though that an increase was seen through arguably offering the assessment at the right time and with time taken to dedicate to addressing carers’ needs. Specifically in relation to older family carers of adults with learning disabilities it has been argued that even where older carers have been identified, most have not had an assessment (Walker, 2005:13). However, as with other carer groups, this is not to say that carers’ needs are not routinely being addressed through a more informal process, what remains unclear though is the efficacy of this more informal approach for carers. Walker’s report does highlight though a move in the right direction (2005:13) in seeing an increase in numbers. She cites the commitment to supporting older carers in Valuing People (England’s equivalent to The Same as You?) as one of the reasons for this. It is perhaps encouraging to note that in South Lanarkshire, approximately a quarter of older carers questioned had already had a Carer’s Assessment completed; the figure may be higher as carers can be confused by the terminology. Older family carers themselves though may also be reluctant to engage in the process for fear of what the assessment may result in (older carers will often say they are managing fine as there is still a deep-rooted fear for some of adults with learning disabilities being ‘taken away’ from the family home). Carers can also feel threatened by (what is arguably a perception) being judged on their ability to provide care. Walker also argues that older carers very much see themselves as parents first and foremost, not really identifying with the label of ‘carer’ (2005:14). Certainly, in the Social Worker’s experience of working with this carer group over the last five years, there is a general feeling from older carers that their needs are bound up with that of their son or daughter and this also supports Walker’s argument (2005:14).

This can also be evidenced with the range of issues that older carers present in needing help with such as adjusting care hours, securing housing, adaptations, reducing social isolation for their son or daughter etc. However, there is another side to this argument in that, as discussed, in order to gain one of these, the carer may need advocacy, information, lines of communication opening up or to negotiate with professionals. Any form of ‘help’ needed can therefore really result in assessing the carer’s needs. This ‘assessment’ in its most basic form is the Social Worker reflecting, ‘what ‘support’ would benefit this carer/what outcomes are we trying to achieve?’. Walker identifies the need for a specialist post in working with older family carers and in assessing need which leads us to look at frontline practice with this carer group.

Practice

The actual practice of offering a Carer’s Assessment to an older carer does not differ from that of any other carer group though as we have heard, deep-rooted fears and misconceptions may play a part in older carers refusing to have their needs assessed. However, through the dedicated
Social Worker’s role, South Lanarkshire Council has seen an increase in assessments taken up when offered by her and in colleagues offering an assessment as part of Time to Think About…; the way in which the assessment is offered is crucial but this also leads us to consider the mindset of the practitioner. If the Social Workers were truly practicing in a ‘carer-centred’ way when completing a Time to Think About… visit, is this why we also saw an increase in the number of assessments taken up? Research carried out in Canada in assessing carers’ needs cites the culture of ‘get in and get out fast’ as a barrier in promoting this area of work; that Social Workers can often view as time consuming (Guberman et al., 2007:583). In a study of the impact of Carers’ Assessments across Scotland carried out in 2006 (Coalition of Carers) the report concluded that they were considered a low priority. Guberman et al., supports this argument referring to a ‘culture of normality’, stemming from Social Workers questioning why carers’ needs should be assessed at all when this is time consuming and there are few resources to meet carers’ needs (2007:58). It is perhaps through supporting older family carers of adults with learning disabilities that we can learn how to structure our approach to Carers’ Assessments but Social Workers are arguably at present practising at diametrically opposed ends of the spectrum (from high risk, crisis driven intervention to what is perceived as low level, preventative work). Paradoxically, most Social Workers want to support carers but arguably feel powerless in doing so. However, a move to an outcome-focussed approach may see Social Workers’ confidence increase; this will only happen though if Social Workers can believe in the outcomes for carers. This leads us to consider the approach with older carers and the outcomes to be gained from dedicated, carer-centred support. Two examples are given here:

**Example 1**

<table>
<thead>
<tr>
<th>Presenting issue/s</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practical help needed in securing suitable housing</td>
<td>Housing meeting arranged</td>
<td>Carer’s anxiety lessened through intensive support until the carer moved house.</td>
</tr>
<tr>
<td>Emotional support needed / stress confounded by unsuitable tenancy</td>
<td>Housing options opened up. Advocacy: liaising with the Housing Officer and all concerned parties</td>
<td>Regular visits and phone calls to the carer-period of intensive support.</td>
</tr>
</tbody>
</table>
### Example 2

<table>
<thead>
<tr>
<th>Presenting issue/s</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support needed - concerns about planning for the future.</td>
<td>A series of visits to chat through carers’ concerns, information given.</td>
<td>Carers feel supported, listened to and their wishes not to formalise plans yet, respected.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Carers gaining trust and confidence in approach taken.</td>
</tr>
</tbody>
</table>

Both examples were ‘formalised’ in the form of a Carer’s Assessment for each case and clearly show that good practice does not have to result in an increase in resources. Though specific to the dedicated Social Worker's approach, Social Work colleagues could just as easily complete these pieces of work but crucially, the time given to each carer would be an issue for many Social Workers at present. The examples also demonstrate how older carers benefit from dedicated advocacy and a counselling approach (the latter drawing on the three core skills of empathy, genuineness and acceptance).

A good Carer’s Assessment will work in many ways not only for the carer but for the Social Worker, who through spending time with the carer (without the service-user present) should be able to gain a clearer picture of the issues for the carer. Where carers are experiencing depression and the Social Worker is needing to assess risk, again taking the time to listen and to talk can constitute a highly effective Carer’s Assessment.

Many Social Workers though need convincing of the worth of a Carer’s Assessment, arguably not so much with the principles behind it but of its value with no resources attached. This brings us back to the issue of practice though and of Social Workers completing a Carer’s Assessment. If a Social Worker can evidence through the Carer’s Assessment that respite is needed, or that care hours need adjusting or that the carer should be prioritised for counselling the Social Worker should evidence the case for meeting the carer’s needs (as they would in arguing for resources for the service-user). Through, again offering this dedicated carer-centred support Social Workers may begin to see outcomes as they do with service-users. The assessment should be used as a tool to evidence an argument. Practice should be thorough and tenacious. There is certainly scope for further research into Carer’s Assessments and practice.

**Shaping support for older carers: Carers’ assessments**

For older family carers, the Carer’s Assessment can be viewed as formalising the support that is to be offered. The assessment itself may be better worded as a Support Plan and as argued, this support should be as personalised as that offered to the service-user. It should be presented by Social Workers as further evidence to support an argument. This may or may not be for extra resources.
The Support Plan could incorporate future planning. This would build on the success of Time to Think About... but across other client groups. Many older carers are supporting people with physical disabilities and/or dementia. They would also benefit from an informal chat around future planning.

South Lanarkshire Council could take an innovative step in asking carers to design a Support Plan in consultation with the local authority instead of what might be traditionally, the other way round. This fits with the idea of co-production (Boyle and Harris, 2009) with equality and not consultation at the heart of practice, ‘It provides an alternative way for people to share in the design and delivery of services, and contribute their own wisdom and experience, in ways that can broaden and strengthen services and make them more effective’ (2009:8).

Any training around Carers’ Assessments for staff should involve or be led by carers, ‘It is essential to have carers or former carers involved in the delivery of training to emphasise the message of empowerment and involvement’ (Heron, 1998:169). This should be done in small groups where possible so that carers and Social Workers feel comfortable in expressing concerns and opinions. Positive outcomes from both need to be highlighted to evidence what the benefits of assessing carers’ needs can be.

Each assessment/Support Plan should conclude with a carer-centred action plan, which the Social Worker should ‘tick off’ as they progress through each action that they will commit to carrying out for the carer. This process should give carers confidence in the outcomes to be achieved.

Where there is a carer, Managers could (in Supervision) confirm with staff that Carers’ Assessments have been offered. Improved practice with carers (evidence-based practice) could also form part of Social Workers’ CPD (continuing professional development) and should be measured not only in the number of assessments offered but of the quality of the assessments completed/outcomes gained, ‘Good practice would indicate that carers should receive clear information about assessment including: its purpose, what to expect in the process, what questions may be asked, their right to have a separate assessment and eligibility criteria for services’, (Heron, 1998:67).

- Staff within day care resources should undergo training in relation to Carers’ Assessments so that they can inform carers of their right to an assessment also.
- Carers should always have a copy of their assessment.
- The assessment should never be offered at a time of crisis; as part of the review process only.

Consideration should be given as to whether there should be a dedicated Social Worker to complete Carers’ Assessments, as with the team for Young Carers completing Carers’ Assessments for children and young people with a caring role within South Lanarkshire. Whilst all the proceeding points are concerned with improving how South Lanarkshire Council can improve the support offered to carers through Carers’
Assessments this dedicated approach would arguably result in a higher number of assessments offered by Social Workers who will want to offer support but will not fear the time constraints, a higher percentage completed and crucially through dedicated carer-centred support this should result in better outcomes for carers as supported from the findings of The Moffat Project. ‘There is no doubt that the Moffat Project had a significant impact on the rates of carers who were informed of their right to an assessment’ (Kelly et al., 2011:ix); this was due to the fact that specific carer dedicated posts were created as pilot sites for this research but the findings also concluded that as a result of the posts created within the system, the overall quality/experience for carers was received more positively, ‘This may explain why carers reported that the experience of receiving a carer’s assessment was more helpful at the end of the project and that carers were more likely to receive additional support’ (Kelly et al., 2011:ix). Parallels can be drawn here with the dedicated post within South Lanarkshire though on a smaller scale.

**Carers’ health**

There is clear evidence of the links between ill health and caring (Yeandle et al, 2007, Carers Scotland, 2011a) and certainly within South Lanarkshire ill health can also be linked to areas of social deprivation (NHS Lanarkshire, 2008). Family carers of adults with learning disabilities are at greater risk of socio-economic disadvantage, and have more prevalent health needs compared with the rest of the population (NHS Health Scotland, 2004:5). Older family carers experience physical and mental ill health alongside other carer groups of course but as we have heard, this carer group also differs from others as ‘lifelong carers’. It is a carer group that as older carers often experiences physical ill health but perhaps of more concern is the emotional impact that providing care for so long has on many. Time to Think About... illustrates that an average of 44% of older carers consider their health to be good. This is the terminology they used in responding to this question. 16% of carers said their health was ‘OK’. It is important to bear in mind the subjectivity of responses here though and to remind ourselves that older carers can still feel ‘threatened’ by Social Workers; answers given may have been underplayed for this reason, which Dillenburger and McKerr’s sample also demonstrates (2010:33) with older carers stating their health is good when in reality they are experiencing numerous health problems. Carers will often ignore their own health needs (Yeandle et al, 2007) to put those of the service-user first and for this reason older carers often carry on providing high levels of care despite experiencing ill health themselves. A study from Carers Scotland concludes that 70% of carers experience physical pain and 86% of carers experience emotional ill health (2011a:2). They concluded that 42% of carers began experiencing health problems after they began ‘caring’.
**Physical health**

Time to Think About... found that 50% of older carers experience significant physical health problems (such as osteoarthritis, diabetes and reduced mobility) with an average of 11% experiencing life-limiting conditions such as those living with cancer. There is not a great differentiation in terms of the data from each of the six areas and therefore the data is not able to illustrate the link between social deprivation and carer ill health. The number of carers through Time to Think About... reporting that their health is ‘OK’ or is ‘good’ is perhaps surprising and it would be interesting to note the specific caring responsibilities and age of the carers who gave these responses as there is evidence to suggest that carers providing over 20 hours of care a week are more likely to experience significant health problems (Carers Scotland, 2011a). Evidence also suggests that there is a correlation between carers in poor health and their negative opinion of services. Research carried out by the University of Leeds found that, ‘their [carers] frustrations in accessing services, and the limited nature of the support they can secure, contribute to their poor health’, (Yeandle et al., 2007:25). Whilst the study focused on carers of working age, this incorporates those 50 and over and also supports the argument that accessing services and support is what can make a real difference to carers’ health and well-being.

For older family carers of adults with a learning disability, it would be interesting to explore whether dedicated carer support does increase older carers’ sense of emotional and physical well-being. Certainly, carers may feel much emotional relief at knowing there is someone to offer support, to mediate and negotiate alongside them. The physical health of an older carer may also improve if dedicated support focuses on for example, an occupational therapy referral, an application for Attendance Allowance, increased care hours etc to relieve some of the physical strain that can be associated with caring. Initiatives such as training for carers (in South Lanarkshire provided by the PRTLCC and PAMIS as examples) can be of great benefit to older carers. Significant improvements have also been made through the Carer Information Strategies, which NHS Boards have developed to help identify carers and their needs. Older family carers in South Lanarkshire often report being called for an annual health check but as with all areas of support, the support/information offered through carers’ surgeries remains better in some areas than others. So, there is still work to do but on the ground things are improving. Little work has been done with G.P.s in raising awareness of the specific needs of older carers through the dedicated Social Worker post though with a Carer Support Team linking into the G.P practices and the hospitals across South Lanarkshire, a gradual shift in carer awareness is taking place. At a national level, there is the potential now to really address how we continue to support older carers. Older carers continue to be supported through ENABLE Scotland but greater joint working is arguably needed with Age Scotland. The very specific health and care needs of older carers of adults with learning disabilities should fall under the umbrella of Older People’s Services, yet older carers may identify more with learning disability services, with organisations that can understand their “world”.
**Emotional health**

This brings us to the topic of emotional health and older family carers and right back to the historical perspective. It is vital to understand why some fears still remain for this client group and why as a group they are ‘unique’. The Same as You? has made a real difference to the lives of many adults within learning disabilities and there is undoubtedly greater acceptance in society of adults with learning disabilities. However, carers of adults with learning disabilities were arguably once stigmatised (Kelly and Kropf, 1995) and still have to deal with other people’s lack of understanding. Older family carers are experienced in dealing with loss, whether consciously or unconsciously and difficulties in accepting loss can manifest itself in anger. Older carers have had a lifetime of change and so when presenting as demanding or complaining services should try to understand why and responses should be led by empathy. Supporting carers with their emotional health is arguably something that we have not got right yet. Time to Think About… identified just an average of 14% of carers who stated they experience emotional health problems. A range of responses were given from not being able to sleep because of worrying to experiencing severe depression. This figure is much lower than expected but perhaps is not a true reflection. It would be beneficial to compare the emotional health of older carers who have seen their caring role greatly reduce in older age (if their son or daughter has left the family home) with those who are continuing to care. Some older family carers interviewed had had past involvement with the Community Mental Health Team. The highest number of carers experiencing emotional ill health was in Hamilton but it may simply be that carers were simply more ‘open’ in their responses here but interestingly, Hamilton had the highest number of carers stating they were supported by family and/or friends.
**Individualised response**

By far the biggest issue in supporting older family carers with their emotional health is in getting the response right. Again, this has to be individualised for it to work and supporting carers in accessing ‘talking therapies’ is also referenced in the new strategy, (Caring Together, 2010). Suggesting to older carers that a stress management course may be of use, whilst it might, this kind of approach is incredibly difficult to ‘sell’. Whilst some carers certainly would and do benefit from this generalised approach, the response from many is that they have not got time to attend a course and if more support was offered then they would not be so “stressed”. Essentially their emotional health often reflects how well (or not) things are going for the person they provide care for. If an older carer is anxious about their son or daughter’s ‘challenging’ behaviour for example, they are likely to choose a personalised response to help ease this anxiety. This might be a referral to the Community Learning Disability Team. Courses and a more generalised approach may offer coping mechanisms but ‘time out’ for older carers such as through respite or even in accessing alternative therapies is often highly regarded. A counselling service for carers was set up in 2007 in one of the London boroughs offering a personalised approach to supporting carers (Community Care, 2008). Though take-up at first was lower than expected, each carer taking part significantly benefited from this individualised approach. The idea of ‘counselling’ is still very much stigmatised and raising the idea of this approach with older carers (even where there is need) is very difficult to do. Evidence suggests that emotional health problems are actually more prevalent than physical health problems for many carers (Hirst, 2004); this study also supports the argument that the intensity of the caring role can increase the risk to a carer’s mental health and that women are most likely to experience psychological distress through providing care, however, the majority of carers are women and may be more likely to admit to emotional difficulties than men are. In relation to older carers, many respond that “you just get on with it”, that providing care for a person with a learning disability is a way of life, of course it can be a very positive experience - though tiring at the same time. A recent study carried out in America suggests that the age at which parents have a child with a learning disability is also a factor in determining how they will manage, psychologically; that the pressures associated with bringing up and supporting an adult with a learning disability attenuates as parents age (Ha et al., 2008). However, there are several factors that can distort this hypothesis such as cultural influences, whether two parents remain as caregivers etc. The research suggests that older parents are ready to ‘parent’ in middle-age and that because a carer is a carer for so long that the parent/carer adapts to stress over time. Further research into the effects of psychological distress in older family carers would need to be carried out though to test this argument in Britain. Comparisons here would also need to be made with other carer groups. At a local level, older family carers are supported with their emotional health through a range of agencies and in working with the PRTLCC, therapies are to be continued to be offered to carers within their localities across South
Lanarkshire. However, further work could be done with older carers of adults with learning disabilities and with other carer groups to better fit emotional support around carers’ needs.

**Shaping support for older carers: Health**

Older family carers would arguably benefit from having access to a Support Worker/Social Worker who is a trained Counsellor or access to ‘fast track’ counselling for carers. This discussion could be opened up with NHS Lanarkshire. NHS Lanarkshire has dedicated Carer Coordinator posts within the three acute sites across South Lanarkshire and findings from The Moffat Project again illustrate how valuable dedicated support can be, particularly in terms of enhancing carers’ emotional wellbeing, ‘the project workers suggested that the emotional support they offer has a significant impact on the carers’ experience and ability to cope’ (Kelly et al., 2011:56).

NHS Lanarkshire and South Lanarkshire Council should consider how best to meet the needs of older family carers experiencing emotional distress (coupled with that of other carer groups) when agreeing funding (Caring Together, 2010). This targeted support could be offered to carers from existing resources but should be a specific carer remit. Consideration should also be given to older carers who experience loss (if the service-user passes away) and any targeted counselling role would incorporate this. Carers should be asked what kind of service would make a difference to them in terms of supporting them with their emotional well-being.

Consider how practical help, at hand and when needed can ease a lot of anxiety for carers. If a carer suddenly becomes ill for example, could there be someone on hand to cover the care temporarily, for a maximum amount of hours as with Birmingham’s Carers’ Emergency Response Team (CERS)? This service was commissioned by the local authority. Carers sign up to a database and receive practical support at a time of crisis, each carer is assisted with drawing up an ‘action plan’ in the event of an emergency (CERS, 2010). This approach could be trialled and funding sought externally for a short fixed term, within the wider remit of exploring emergency responses as referenced in South Lanarkshire Council’s Carers’ Strategy (2010). This could result in freeing up carers to attend their own health appointments for example, to go into hospital as day patients, for carers to be able to think about themselves and their own health needs; resulting in an economically viable carer pathway in terms of a preventative approach.

South Lanarkshire Council should record carers’ ages, which could be used to plan for services, housing and support for older carers (Martin and Johnston, 2005).

A Life Plan for older family carers could be developed to ease anxiety. This builds on the individual visits carried out through Time to Think About… However, discussion would be needed as to how this could be executed. Concerns have been raised by carers of detailed plans being drawn up only to be put in drawers and never reviewed. Further work would need
to be done in this area but is something that should be looked at. Various models exist such as the Life Review process, which is a therapeutic technique based on an ecological perspective (Kropf and Greene, 1993). This addresses older carers’ life stages as well as coping mechanisms within their social system. A Futures Planning model has been developed in Australia, which also incorporates a great deal of information on the service-user (Cartwright et al., 2008) and both are good examples in supporting older family carers.

Through Personalisation there is great scope to increase carers’ health and well-being though for older carers and for Social Workers, this still remains a very new concept. Older carers very much worry about the complexities of personal budgets but in a recent article in Community Care, again a London borough was commended for its approach to increasing the take up of personal budgets to older carers (2010:9). Cited, is an example of a 103 year old carer who looks after his 66-year-old daughter with a learning disability, using money allocated for traditional respite for a holiday for him and his daughter and paid carers to push their wheelchairs. The resulting outcome from their budget suggests this meets the carer’s and his daughter’s social and emotional needs. Joint working through pooling budgets for older carers and adults with a learning disability could greatly improve outcomes for older carers.
**Conclusion**

Time to Think About... developed from the identified need to ameliorate practice with this specific carer group in supporting older family carers in thinking about planning for the future, for anxiety to be lessened and for carers to have quite simply benefited from chatting through their concerns and/or plans. This is juxtaposed with an outcome-focused approach in moving to support carers this way and fits neatly with the move towards anticipatory/preventative care planning.

Time to Think About... is perhaps a unique approach to supporting older family carers of adults with learning disabilities. The approach was intended to increase the support offered to older family carers in thinking about making plans for the future and to help shape future planning at South Lanarkshire Council. This report aims to do the latter and from feedback gained from carers the visits (dedicated to their needs) have been useful in the main. There are certainly limitations with the approach taken though. For a few carers, the visits will not have made a great deal of difference and only informal feedback was given by carers and Social Workers. The sample (166 visits) is biased in that all carers were aged 50 and over and generally were White, Scottish in ethnic origin. Interviews were not taped but recorded in writing and so the data gained, though rich in shaping emergent themes is highly subjective. As discussed, older carers will also ‘fear’ the Social Worker’s perception of them and the power imbalance at the interview must be incorporated into the bias. There were exploratory themes that led this piece of work rather than a hypothesis and though the Social Worker is confident that the data retrieved was done so with empirical rigour, this is not action research in its purest form. It was the Social Worker’s intention to improve practice with older carers first and foremost; a standardised approach at recording the visits evolved alongside this.

From the findings we have seen that older carers do wish to think about the future and in the main have benefitted from an individual response to their needs in relation to this. We have seen older carers take a proactive approach to future planning when prompted, when given the support and information to do this. Much good practice in supporting carers in embedded in a partnership approach within South Lanarkshire and older carers continue to be well supported by South Lanarkshire Carers Network and The Princess Royal Trust Lanarkshire Carers Centre. The visits to older carers have also highlighted areas for further development though such as in more individualised responses (a carer-centred approach), addressing emergency planning, looking at how we support ageing carers with their own health needs, our approach to assessments and to meeting housing demands. Some carers of adults with learning disabilities continue to say how well South Lanarkshire Council does meet the needs of their relative (with the Carers’ Partnership in Practice Group highlighting that keeping day centres in South Lanarkshire was particularly beneficial, albeit now termed integrated community facilities). It is through Time to Think About... though, through listening to carers on the ground (within their own homes) that we can begin to think about improving things further.
Though in these times of tough economic challenges a specific post dedicated to older carers may be seen as ‘luxury’ the efficacy of the post should be measured against its achievements and within the wider context of improving support for carers. There are many examples in England of specific support for older family carers within local authorities (Magrill, 2005) but arguably much less so in Scotland. The demands on one worker though are increasing and this is without ‘promoting’ the post. Recent research carried out by The Social Policy Research Unit (SPRU) concludes that families involved in the ‘transitions’ stage benefit from having a dedicated post within the system and experience better outcomes as a result (Sloper, et al., 2011). Certainly, the same ‘priority’ should be afforded older carers as younger parents/carers and whilst specific posts may be questionable, they arguably emerge in the first place because of unmet need in one way or another.

Scotland’s new Carers’ Strategy can be welcomed as the first step in addressing the needs of older carers and Learning Disability Alliance Scotland through their Charter for Change has highlighted that better planning with older carers should make a huge difference but at little cost (Naysmith, 2010). The way in which we approach older carers, the information we offer, the personalised approach can make a huge difference on so many levels.

Time to Think About… places an emphasis on planning at a time of transition and though many older carers will continue to campaign for more resources, the data collated from this approach suggests that a low level approach can be effective but the need to invest in services for adults with learning disabilities cannot be ‘brushed under the carpet’. Research conducted by Eric Emerson and Chris Hatton at the Centre for Disability Research at Lancaster University evidences that, ‘the number of people with learning disabilities who need social care is growing up to five and a half times faster than the government [Westminster] has planned for’ (Agnew, 2009:12). This study was based on school census data for the first time to assess future need. Demographic changes such as older mothers having children, medical advancements and adults with learning disabilities outliving older parents should move local authorities to act - and if starting off with low level support is the way forward then so be it. South Lanarkshire can at least be re-assured that it is starting to work away at the issues.
Recommendations

Given the points for discussion/good practice made at the end of each section and the justification put forward for these, broad recommendations will be made here as South Lanarkshire Council should take note of the specific points made in terms of shaping service design. Recommendations are as follows, derived solely from the data analysis and emergent themes:

- South Lanarkshire Council should continue the development work to better address the needs of older family carers.
- Findings from this report should be disseminated to staff within South Lanarkshire Council, to partners and carers.
- Consideration should be given to researching and developing a toolkit for supporting older family carers to standardise practice.
- Legal provision should broadly be addressed as part of the review process as it stands so that older carers can be supported in future planning.
- The quality of the Support Plans/Carers’ Assessments offered to older carers (and other carer groups) should be monitored alongside numbers.
- Emergency planning for carers should be developed and reviewed with carers, partners and colleagues.
- Older carers’ health and social care needs should be taken into account when looking at future planning and a consistent, strategic approach taken.
- Consideration should be given as to how a growth in the numbers of adults with learning disabilities requiring housing and support can be met. Work should start on collecting data in light of this report.
- Older carers should continue to receive good, up-to-date, timely information in relation to future planning.
- Consideration should be given to whether the current practice model in working with older family carers of adults with learning disabilities should be reviewed with a view to a more individualised response to working with carers.
Time to Think About…

Guide for Staff - Background

In 2005 South Lanarkshire Council commissioned a piece of research looking at the needs of carers over the age of 50. A report of the findings was published entitled: Older Family Carers and Learning Disabled Adults Cared for at Home. The research was carried out by Mike Martin and Lucy Johnston. Copies are available.

The aims of the research were to learn more about carers (50+) of adults with learning disabilities, to understand their needs, look at how services might meet these and to look at the provision of future planning.

Statistical Findings

The Council (at that time) was aware of 332 family carers (50+) supporting an adult with a learning disability at home. South Lanarkshire Council knew of just over 1000 adults with a learning disability. 42% of the carers identified were lone parents. In South Lanarkshire over a quarter of the carers identified were aged over 70. Three fifths of family carers (50+) described their health as ‘less than good’. A third reported spending more than 12 hours each day on care tasks.

Summary of Report Findings

- Some carers found benefits in accessing carers’ groups in terms of sharing information, gaining support and for social contact. Others found groups lacking in structure, taken up by personal agendas and that they served as a ‘talking shop’ only.
- The need for more respite was highlighted, but some carers did not feel they needed any help.
- The report identified that most carers are unaware of the support out there for them, but that they wished to be informed of support, that they are not ‘seekers’ of it.
- The report found that many family carers and service-users are ill prepared for the future and just over a third have a plan in place should an emergency arise.
- Only five families said Social Work Resources was aware of their long-term plans for the future and just three families had consulted a Lawyer. 27% of families reported actually having a long-term plan.
- Carers believe that there is an important role for day services to play in supporting service-users with future planning, including supporting individuals in developing independent living skills.
- Housing issues were considered most important with the right amount of support being crucial. Carers were concerned about ‘vetting’ of support workers and lack of continuity of staff. Nearly half those questioned wanted their son/daughter to remain in the family home with support, but only four families had done something about this in terms of planning.
Summary of Conclusions

- Whilst the service-user is at the heart of any planning, a ‘whole family’ response is needed where possible.
- Many families have a preferred housing option, but the level of skill and experience of the service-user may be at odds with the option preferred.
- Few carers know of the services available in South Lanarkshire.
- Few carers understand the process of accessing housing/housing support services.
- Crisis intervention remains inevitable with the lack of future planning made.

The Scottish Executive in their response to Care 21 – The Future of Unpaid Care in Scotland states that where Carer Strategies are working well carers will be “signposted to local advice, usually voluntary sector carer centres. That way Carers will be systematically made aware of their rights as well as a range of practical support services”. This is part of the aim of the visit as well as to raise the issues of planning ahead.

Carers are now identified as key partners in care, but a recent Social Work Inspection Agency report recorded that “only 52% felt consulted and listened to as Carers”. Carrying out some ‘one-to-one’ work with carers aims to improve this figure.

Supporting Carers

In terms of future planning, South Lanarkshire Council is aiming to:

1. Improve the information given to carers
2. Offer carers’ workshops/local carers’ events
3. Visit carers (50+), record and listen to their concerns and those of service-users
4. Raise awareness of services, Carers’ Assessments and housing options
5. Look at developing a screening system, which identifies those carers over the age of 50 most in need of support
6. Develop an information pack to guide carers through the future planning process
7. Address emergency planning

References:


Scottish Executive Scottish Executive Response to Care 21 Report: The Future of Unpaid Care in Scotland Scottish Executive, Edinburgh, 2006

Claire Pearson
October 2006
Appendix 2 - Visits guide for staff

Time to Think About...

Guide for Staff in Visiting Carers

- Visits identified for each social worker by the Team Leader and I
- I will email you individually with the names of those we would like to ask you to visit
- Letters will be sent to the carers identified to outline what the visit/interview is about
- I will let you know when the letters have gone out and you are free to make contact then by phone to ask if you can visit
- The visit is aimed at carers; in most cases service-users are not present. Further work may need to be followed up with service-users (and their Advocate where applicable)

The Visit:

- Record the visit on the proforma (one copy in the file, one to Claire)
- Briefly record the visit on the I38 (case records)
- Ensure the carer has a copy of the resource pack
- Any further information needed, photocopy this and send onto the carer/contact me

Any queries, you can contact Claire Pearson (Social Worker, Supporting Carers of Adults with Learning Disabilities: 01698 455546).

Thank you.
Dear Parents/Carers

My post at South Lanarkshire Council is to look at ways of supporting carers of adults with learning disabilities. Part of this involves future planning and as a result I am working with our social work teams across South Lanarkshire in visiting family carers to chat through plans for the future. We have called this piece of work, Time to Think About… Along with carers and colleagues, I have developed a resource pack of the same name, which you should have received through the post.

The visits are just a ‘one off’ piece of work at this stage, an informal chat with the chance for carers to gain information and to ask any questions around future planning.

Responses we receive from carers around their plans will be kept confidentially on file, though general feedback from visits will be written up in the form of a report when all visits are completed.

We fully respect that some carers will not want to chat over their plans or that this may not be a good time for some. If you would not like to take part, then please telephone me on: 01698 455546.

If you are happy for a social worker to contact you with a view to talking over future planning, I will ask a social worker from your local team to make contact with you over the next few months.

If you have any queries at all, then please do not hesitate to contact me.

Yours sincerely

Claire Pearson
(Social Worker Supporting Carers)
Appendix 4 - Proforma for interviews

Time to Think About…

Recorded to express the wishes of the carer(s) in planning for the future.

Name of carer(s)

Carer's DOB

Name of service user

SWIS no

Date of interview

Present at interview

Future needs discussed

Financial/Legal Issues

- Has the carer POA or Guardianship? Please state yes/no
- Has the carer a Will? Please state yes/no
- Is a Trust Fund in place? Please state yes/no
- Is the carer the Benefits Appointee? Please state yes/no

Comments
Housing Options

- Has a housing application actually been made?
- Have applications to other social landlords (as well as SLC) been made?
- What time scale are we looking at (how ‘pressing’ is the need for a house/flat)?
- Is 24 hour care needed?
- What is the carer’s wish for future housing?
- What is the social worker’s assessment for future housing?

Emergency Planning

- What are the carer’s plans/wishes should an ‘emergency’ situation arise?

Current Support for the Carer

- Has the carer had/been offered a Carer’s Assessment?
- Are any support groups etc accessed?

Carer’s Current State of Health


Any other comments


One copy to be sent to Claire Pearson at (or by email):

Social Work Resources
4th Floor
Brandon Gate
1 Leechlee Road
Hamilton
ML3 0XB

One copy to be kept in the service-user's file

Future planning pack/resource guide should already be with the carer
Emergency Planning for Carers

Checklist for Carers in Emergency Planning:

- Have I got a Carers Emergency card?
- Have I registered with Lifeline (emergency information scheme)?
- Is the alert alarm installed?
- Do I have copies of an up-to-date Care Plan and a Community Care Assessment?
- Have I had a Carer’s Assessment?

In an Emergency (for the carer to complete with the cared for person and an employee from Social Work Resources):

My name is

My date of birth is

I provide care for

In an emergency it is my wish that

It is the cared for person’s wish that
**Emergency contact(s)**

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<tr>
<td>Address:</td>
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<tr>
<td>Relationship to carer:</td>
<td></td>
</tr>
<tr>
<td>Home phone number:</td>
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<tr>
<td>Work phone number:</td>
<td></td>
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<td>Mobile number:</td>
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<td>Spare key (yes/no):</td>
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<td>Address:</td>
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<td>Mobile number:</td>
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<td>Spare key (yes/no):</td>
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**Next of kin is:**

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<th>Phone number is:</th>
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**Is there a key safe?:**

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<th>Who has the number?</th>
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**Does anyone have guardianship or power of attorney?**

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<th>Yes/No</th>
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<th>Phone number:</th>
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**Who can legally access money/benefits in an emergency?**

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**Information on the person/s I provide care for is kept in**

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**Information on their health/medication is kept in:**

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Numbers I might need in an emergency:

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<tr>
<th>My GP is:</th>
<th>Tel:</th>
</tr>
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<tbody>
<tr>
<td>Emergency Service</td>
<td>999</td>
</tr>
<tr>
<td>NHS 24</td>
<td>0845 24 24 24</td>
</tr>
<tr>
<td>Social Work office phone number</td>
<td></td>
</tr>
<tr>
<td>Out of hours I can ring in an emergency</td>
<td>0303 123 1008</td>
</tr>
<tr>
<td>Care agency name</td>
<td></td>
</tr>
<tr>
<td>Phone number</td>
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<td>Care agency name</td>
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<td>Phone number</td>
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<tr>
<td>Other important names and numbers</td>
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Condition Specific Information Held on the Cared For Person:

- There is an Anticipatory Care Plan: Yes/No
- There is an Advanced Statement: Yes/No
- There is a Community Learning Disability Team Emergency Plan: Yes/No

This is kept in

The following people have given permission to be named on this form:

The following people have copies of this form:
I give permission for Social Work Resources to hold a copy of this form:

Signed: 
Dated:  

Copy of this form passed to the carer  Yes/No
(í.e. In a plastic wallet) to be kept by the phone

To be updated once a year. Last updated:
References


Carers Scotland (2011a) Sick, Tired and Caring. Glasgow: Carers Scotland


Community Care and Health (Scotland) Act 2002. Edinburgh: HMSO

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Parliamentary Debate (2010) Carers and Young Carers' Strategy. (S3M-7272)


South Lanarkshire Council eSAY Return (2011) Hamilton: South Lanarkshire Council


Williams, C. (2007) ‘Scots Pioneers’ Community Care 6 Dec, 32


