



Short Breaks for Adults with a Learning Disability

SUMMARY

- 1.1 This report provides a summary of the consultation responses to the proposed changes in how adults with a learning disability are offered short breaks, involving ceasing the residential respite service currently offered at Ashlea Hostel, a 22-bed care home managed by the Council. It also provides a summary of the findings from the Equality Impact Assessment that has taken place involving key stakeholders.
- 1.2 The report recommends that short breaks need to be available in a range of ways, taking into account the needs and preferences of the disabled person as well as those of their family carers. It supports the position of the Council continuing to develop its Shared Lives scheme to provide community based short breaks whilst recognising that further work to identify appropriate alternatives to Ashlea Hostel for those with the most complex disabilities may be required.

RECOMMENDATION

- 2.1 To note the draft recommendations to be presented to Council Cabinet on 7th November, detailed below:
 - 2.1.1 To note the consultation responses and outcome from the Equality Impact Assessment as detailed in Appendix 2.
 - 2.1.2 To close the existing service offered at Ashlea Hostel by 1st April 2013, subject to the satisfactory provision in 1.2 being fully met.
 - 2.1.3 Post 1 April 2013 to offer a continued residential service at an existing Council facility for those individuals with the most complex needs to enable detailed planning to identify suitable alternative accommodation and to review those interim arrangements before September 2013.
 - 2.1.4 To support the proposal that the Learning Disability Service will develop a contingency plan with each individual and their family that sets out what will happen should there be an emergency or unplanned need for support.

REASONS FOR RECOMMENDATIONS

- 3.1 The proposal to close Ashlea Hostel is in line with the aim of providing affordable, community based support tailored to the interests and needs of each person. Personal Budgets would continue to be offered to all individuals using that service

and many people will be able to replicate their current level of short break through using more cost effective and personally tailored support arrangements, such as the Shared Lives scheme or through a Direct Payment.

- 3.2 The use of Ashlea Hostel has been gradually declining in recent years as young people in particular are choosing alternative ways of having a short break. Since April 2011 this has reduced from 99 to 58 and many of those remaining are actively pursuing alternative options, such as the Council Shared Lives Scheme. Increasingly, those using Ashlea Hostel have higher and more complex support needs and require use of the rooms with space for specialist equipment and large wheelchairs and/or higher ratios of staffing support due to behavioural and/or healthcare needs. Working within the current staffing establishment and the rooms fit for purpose has therefore meant reduced occupancy.
- 3.3 The Ashlea Hostel building suffers from problems with legionella, which, whilst being managed and ensuring the safe use of the property, is at a cost of approximately £1000 per month, therefore adversely impacting on the suitability of the building.
- 3.4 The profound healthcare needs of some people using Ashlea mean that identifying suitable alternative arrangements and securing appropriate Health funding is likely to be a longer process and will require careful planning. Discussions are underway with Derbyshire PCT regarding their role and potential availability of beds in the county within easy reach of Derby.
- 3.5 Offering an extended service to those families will enable detailed planning to continue beyond the end of March if needed, to explore community based options that may be appropriate, to prepare for any new arrangements and to enable a smooth transition, ensuring the needs of the person and their family carers can be fully met.

SUPPORTING INFORMATION

- 4.1 A review of the residential respite service at Ashlea Hostel was conducted between September 2010 and July 2011, involving customers, carers, staff and the Trade Unions. Many customers and their families said they would like a wider choice and different ways of having a short break. Others said they were happy with the service they had at Ashlea. The review set out a clear case for change and, as a result, action was agreed to support people to have more choices in how they achieve a short break. The number of people using Ashlea has reduced as a result of this work as people are increasingly finding other ways to have a short break. The recommendations set out in this report build on that work and are a direct result of that review.
- 4.2 Short breaks serve family carers who need the break to be able to continue in their caring role. However, the break must be a positive and fulfilling experience for the person too. People with a learning disability, nationally and locally, are voicing their preferences to have breaks in other ways that not only are more socially inclusive but that promote their independence and confidence, developing skills and social networks outside the family home. They can use Direct Payments to fund a Personal Assistant to support them in a variety of ways, depending on the specific interests of the person; an evening swimming or taking part in evening classes or socialising locally and accompanying them on an overnight stay. Some people have breaks together and use activity centres, holiday chalets or hotel deals, pooling their money to fund support and transport. Others pay for support in the family home if that is most appropriate. These examples often cost much less than residential respite and offer a more fulfilling experience. Some case studies are summarised in Appendix 3.
- 4.3 The Council's Shared Lives scheme offers opportunities for the person to build a relationship with a local family and take part in activities with them, offering flexible and bespoke support and extending the person's social contacts and confidence outside the family home. This scheme is attractive to many families who have previously used the service at Ashlea and as applications from people keen to become approved carers grow, the number of people able to be matched with another family is growing. Families of three customers with complex physical impairments have stated that, should a decision be taken to close Ashlea, they would be willing to explore using Shared Lives carers.
- 4.4 Notwithstanding the reduced occupancy, Ashlea was £48,604 over budget in 2010/11. Registered residential provision is inherently a very expensive way of meeting needs and the net impact of the reduction in capacity is that the cost of Ashlea per overnight stay has increased in recent years; the average cost is now £149 per night with the total cost for some customers over £350 per night. In addition, the site continues to suffer from problems with legionella, which, whilst being managed and allows the safe use of the property, is at a cost of approximately £1000 per month, therefore adversely impacting on its future suitability.
- 4.5 Since the beginning of the consultation exercise 12 individuals have been successfully supported by the Shared Lives scheme and are already reporting very high levels of satisfaction with those arrangements. A further 21 are currently in

the process of getting to know potential carers and being 'matched'. This includes some families from BME communities who are being matched with carers from those specific communities. 17 family carers have stated that they are definitely not interested in Shared Lives and 14 have stated a reluctance to pursue Shared Lives until the future of Ashlea is confirmed. The typical cost of a night with Shared Lives carers is £57 and approximately 10% higher for people with more complex needs.

- 4.6 On 11th July Cabinet agreed that public consultation would take place on the details of the proposals. A 12 week consultation period ran from 16th July until 13th October 2012. The consultation sought views on the following proposals:
- The Council should cease to provide a service at Ashlea and the building will close;
 - In its place, the Council will continue to ensure people with eligible needs are able to have a short break by giving everyone a Personal Budget. People will be supported to choose what sort of short break they would like – whether it is a more socially inclusive option or a more traditional service in a residential care home.
- 4.7 In addition, Council Cabinet instructed officers to explore the feasibility of the Council providing an alternative, smaller scale, building-based short breaks facility for those people with profound and multiple disabilities, accessed via individuals' Personal Budgets.
- 4.8 **Consultation analysis** - the main vehicle for consultation was hard copy questionnaires which were available in two versions, one being easy read. An on line survey was also available on the Council's website. The Council commissioned a local, independent self-advocacy organisation to meet with people with a learning disability, organising small group meetings, facilitating workshops and meeting people individually where requested. In total, 94 people with a learning disability attended such meetings. Through this process, people were supported to complete easy read questionnaires or have these completed on their behalf. 116 such questionnaires were received as well as summary notes taken from the eight meetings that were organised during the course of the consultation.
- 4.9 Council officers attended four group meetings with family carers with notes taken as part of the public consultation. The majority of family carers at those meetings were those whose relatives currently use Ashlea. In total there were 144 general questionnaire responses received as well as written representations from a small number of family carers and people with a learning disability.
- 4.10 In addition, 15 submissions were received via Unison as part of their 'Save Our Care Services' campaign. These were predominantly from family carers whose relatives go to Ashlea for short breaks. Despite being received after the consultation end date, these are referred to in the interests of transparency. In summary, these comments stress the importance to family carers of having regular respite, the peace of mind it gives them knowing their relatives are well cared for, the quality of care received at Ashlea and the importance to people with a learning disability to see friends, to have a routine and familiar surroundings.
- 4.11 The key themes that have emerged from the consultation are as follows:

- There was a strong desire for people with learning disability to be supported in other ways to have a short break in the community and to exercise choice in how they are supported;
- There was general support for the use of the Shared Lives Scheme for short breaks although many people felt that this would not be appropriate for everyone;
- There was a strong desire for (a) there to be a residential respite facility, particularly for those people with the highest support needs and (b) for the Council to be the provider;
- The majority of respondents were not supportive of Ashlea closing.

4.12 Below is a summary of the specific consultation points with proposed amendments/ responses highlighted in italics.

4.12.1 **Feedback on whether adults with learning disabilities should have a range of choices in how they take their short break –**

There was support for the suggestion that people should have breaks in a range of ways. 85% of people with a learning disability who responded stated that they should have choice in how they get a short break. When asked what breaks people would choose, a wide range of responses were received such as going walking in North Wales, a weekend in London and visiting other relatives.

In the general questionnaires 88% of respondents agreed or strongly agreed that people should have a range of choices in how they take their short break and 86% felt that people should be able to have a short break that includes a range of leisure and community based activities. 76% agreed or strongly agreed that people should be able to have a short break which is more 'ordinary' such as staying in a hotel and 91% of respondents agreed or strongly agreed that people should have a choice in who they are supported by and who they spend their time with on their short break.

4.12.2 **Feedback on whether Ashlea Hostel should close or remain open –**

The majority of respondents felt that Ashlea Hostel should not close. 58% of respondents with a learning disability expressed this view and 27.5% were not sure. 57% of other respondents stated that Ashlea should remain open and 36% stated that they didn't know.

4.12.3 **Feedback on the suitability of Ashlea Hostel for people with complex needs –**

35.7% of respondents with a learning disability stated that they agreed with the statement that Ashlea Hostel may not be suitable for everyone whilst 40% stated that they weren't sure. Asked about the suitability of Ashlea Hostel for people with complex needs, 46.6% of people using the general questionnaire stated that they felt it was 'suitable' or 'very suitable' and 36.4% stated that they didn't know.

4.12.4 **Feedback on whether the Council should ensure overnight residential accommodation is available for adults with profound and multiple learning disabilities who need it?**

There was strong support for the notion that the Council should ensure residential accommodation is available for people with profound and multiple impairments. 91% of respondents using the general questionnaire agreed or strongly agreed

with this suggestion.

There needs to be further work to explore the availability of residential respite provision once the funding entitlements and healthcare needs of those individuals with profound and multiple impairment are confirmed.

4.12.5

Feedback on whether Shared Lives is a good option for some people to have a break -

There was general support for the use of the Shared Lives scheme with 55% of respondents using the general questionnaire stating that they agreed or strongly agreed that it was a good option. Qualitative feedback received reinforces this view that whilst many people support it in principle there is concern that the scheme is not appropriate for everyone.

It is proposed that the Shared Lives scheme undertake a targeted piece of work to recruit carers specifically who can cater for the needs of people with complex behavioural and physical impairments. This would need to include considerations in relation to the accommodation and the training and experience of those carers.

4.13 **Equality Impact Assessment** – An Equality Impact Assessment (EIA) was updated following feedback throughout the consultation period.

This was shared with family carers, Ashlea staff and managers, trade unions, advocacy groups and Health colleagues.

4.13.1 The EIA noted the positive impact that the service at Ashlea has on the lives of family carers and, in particular, older family carers and those whose relatives have more severe impairments. It is recognised that ceasing to provide a service at Ashlea Hostel will bring risks which are highlighted in the EIA. These include:

- the need for those in paid caring roles supporting people with profound and multiple impairments to be suitably experienced and trained and that if there is not sufficient time to ensure any new carers fully understand the person and their needs this could adversely impact their quality of care provided.
- The need for an appropriate length of time to put in place any changes to the caring routines, including the introduction of any new carers for those individuals with profound and multiple impairments. It is recognised that many people find change difficult and disruptive and the length of any transition period needs to take this into account;
- The need for support at very short notice (whether or not this is described as an ‘emergency’) is vital for many families. Arrangements will need to be agreed that are appropriate for each individual and their families in order to ensure that support can be responsive and flexible according to their needs;

4.13.2 In order to reduce any adverse impact of the recommendations, the following actions are included in the EIA:

- To make use of a regionally funded project to raise awareness of short breaks and personal budgets to support family carers using Ashlea to be fully aware of alternative ways of having short breaks;
- To ensure that the healthcare needs of customers with profound and complex impairments are fully assessed and addressed and that the availability of residential resources within the county are confirmed at the

earliest possibility;

- To provide an extended residential facility for short breaks following any closure of Ashlea Hostel in order to allow sufficient time to fully explore wider choices for those individuals, acknowledging their very specific needs and to ensure a careful transition to any new arrangements;
- To continue to grow the Shared Lives scheme, including the recruitment of carers from BME communities and those with accommodation and expertise that is appropriate to meet the needs of customers with complex impairments.

Emergency Care

4.14

Ashlea Hostel has offered an emergency service for people who, due to a family crisis or break down in existing support arrangements, have needed overnight support and accommodation at very short notice. During 2012 there have been 7 such admissions to date. Due to the bed space at Ashlea, it has offered a relatively easy solution in those situations. However, the majority of people who have used it on such a basis have not been living with family carers but in other supported accommodation and, once at Ashlea, many have stayed well beyond the date they were due to leave. This has meant that Ashlea has been offering long term residential accommodation for a small number of people, of which two currently remain and who are in the process of moving to alternative accommodation.

4.14.1

It is acknowledged that some people will experience placement or tenancy breakdown but such individuals rarely need to be moved into a residential respite facility. As such, it is recommended that other, more personally tailored support arrangements should be put in place to sustain their existing home or to move to another residential home.

4.14.2

Similarly, it is acknowledged that families, from time to time, will need their relative to be cared for at very short notice due to unforeseen circumstances. It is suggested that for this eventuality, each person have in their Support Plan a contingency plan for how such support will be available should the need arise and that this be quality checked by the Council when approving the Support Plan. Providing emergency registered residential care beds for such an eventuality is a very expensive, and often totally inappropriate, way of meeting the need. Many Shared Lives carers currently provide 'emergency' care at short notice and it is suggested that the number of these be increased.

4.15

Support Planning with families should continue in earnest over the coming weeks to identify ways of providing a break tailored to the needs of the person and using the Personal Budget to identify affordable ways of achieving this, enabling the family to have the level of breaks they require. This work should be done with the aim of everybody who can be supported in this way ceasing to use Ashlea Hostel within three months.

4.16

During the time between December and March, however, the service at Ashlea Hostel should move towards one that operates on a reduced staffing establishment, catering solely for those individuals in transition to new arrangements and those with more profound and complex impairments. Note that due to reduced demand in November and December the service is already

planning to condense its usage to a maximum of 5 beds.

- 4.17 Arrangements to meet the needs of the people with more profound impairments will need to be planned in earnest and this will necessitate further dialogue with PCT and County Council colleagues. Final arrangements for those people will be known pending the outcome of those discussions and assessments; but it is recommended that in the meantime the service at Ashlea Hostel be remodelled to provide a targeted service for those individuals until 31st March 2013. This will not require capital expenditure but will require a review of the staffing model and structure.

- 4.18 During this time plans would be developed to enable the Council to accommodate a separate unit for people with profound and multiple impairments within an existing Council service. This would potentially happen within a residential home supporting older adults where there could be a specially developed and discrete unit for individuals transferring from Ashlea Hostel. The transition would be managed sensitively and would be cost effective with shared management and running costs of the building. Some of the existing Ashlea staff would transfer to the new facility and provide the continuity of care required.

OTHER OPTIONS CONSIDERED

- 5.1 **Option 2: The continuation of the service offered at Ashlea Hostel with no change;**
- 5.1.1 The reducing demand and resulting increased cost means that this would be a highly expensive service in addition to the running costs of the building alone. This option would mean that many people who do not need to stay in a residential care home to have an overnight break would be denied opportunities for having those breaks in other ways as the money could not be released to enable them to exercise choice. It would also not be affordable within the allocated Personal Budget amounts for those individuals and not, therefore, fit for the future in the light of personalisation and fair and affordable support based on people's needs.
- 5.1.2 Continuing to operate the service as it is would therefore mean that there was a disproportionate expenditure on short breaks for a relatively small number of families and, as such, the Council would not be supporting all families of people with learning disability fairly and equitably based on a socially inclusive model.
- 5.1.3 Budgetary savings for 2012/13 and 2013/14 totalling £270,000 would need to be found from elsewhere as the savings target assumes that people will be offered a Personal Budget with the savings released from the Ashlea Hostel budget.
- 5.2 **Option 3: The development of a new residential service managed by the Council catering for approximately 20 people.**
- 5.2.1 Analysis of the levels of demand and support needs for the 19 people with complex and profound impairment has been carried out. This indicates that, based on full bed occupancy over a year, approximately 3 beds would be needed. This scenario, however, is unrealistic and therefore a 5- bed facility, offering some economy of scale and providing some capacity for people with lower levels of need who wish to purchase such provision would be reasonable.

- 5.2.2 Estimated revenue costs: Staffing costs for providing a Council managed 5 bed facility would be approximately £350,000 based on existing staffing models and could reduce were these to change. However, it is still likely that the costs would remain over £300,000. Typically, staffing costs equate to 80% of running costs so the actual costs of provision would likely be an additional 20% (£70,000). Based on a conservative cost of Council managed provision at £370,000, the nightly rate, based on a 5-bed unit with 100% occupancy, would be £202.
- 5.2.3 Revenue available: Financial modelling for the Modernisation Project assumed more community based options and therefore residential short breaks costs (which are typically £140 - £300 per night) were not factored in and short breaks amounts of approximately £110 social care funding have been assumed for these customers. The net result is that there would be a shortfall of £282,000 recurring revenue, some of which may be able to be offset with Health funding for the individuals involved. In addition to this, the savings target for 2013/14 of £135,000 would be unable to be met.
- 5.2.4 This option would involve capital investment or leasing and such costs are estimated to be in the region of £1.5 m assuming that any new facility is built on an existing Council Owned site. In addition should the council opt to build to fund this option would require borrowing which would in turn mean that borrowing costs would be required to be met from revenue.
- 5.2.5 Given that the cost of providing a new residential service using Council funding alone is not viable, it is recommended that this option not be pursued.

This report has been approved by the following officers:

Legal officer Financial officer Human Resources officer Service Director(s) Other(s)	Olu Idowu Toni Nash and Nicola Goodacre Liz Moore Brian Frisby N/A
For more information contact: Background papers: List of appendices:	Jenny Pitts 01332 642741 e-mail jenny.pitts@derby.gov.uk None Appendix 1 – Implications Appendix 2 – Equalities Impact assessment (to follow) Appendix 3 – Case studies Appendix 4 - Consultation summary analysis

IMPLICATIONS

Financial

- 1.1 All customers currently using Ashlea Hostel have had an updated assessment of their needs and have been allocated an indicative Personal Budget amount using the Council RAS (Resource Allocation System) and information regarding cost of the current service and individual assessed need. Support planning with those individuals choosing Shared Lives carers or a Direct Payment is showing that their need for short breaks can be met within those amounts.
- 1.2 Those with higher support needs and who prefer to use a residential respite service will potentially require additional Healthcare funding to meet their individual personal healthcare needs. Continuing Health Care entitlement has been confirmed for 5 of those individuals and assessments and outcomes for a further 10 are still awaited. Indicative Council Personal Budget amounts for those customers are approximately £110 per night based on a typical 40 night per year usage. As such this makes the affordability of residential respite at current levels only possible if there is additional Health monies to contribute towards the cost.
- 1.3 The savings in 2012/13 and 2013/14 to enable the Council to achieve a balanced budget total £270,000. The base budget for this financial year, at £529,271 already assumes the first year of those savings. Given that not all customers have yet moved to purchasing a short break with their personal budget, the savings target for 2012/13 has not yet been fully met.
- 1.4 Financial implications of the recommended option would involve some capital refurbishment to an existing Council service to ensure the specific needs of the individuals using it could be properly met.
Estimated revenue costs would be:
2013/14 £145,000 estimate for 6 months (based on shared management arrangements and £5000 contribution to running costs, utilities etc.) meaning that the savings target of £135,000 for that year will not be met) and there would be an overspend of £10000.
Capital costs of the recommended option are expected to be minimal as it appears likely that the needs of the Ashlea customers in question could be easily met within an existing Council property with one off costs required for minor internal works, installation of ceiling tracking and registration and removal costs. Further work will be carried out to ascertain the detail of such refurbishment following any Cabinet approval.

Legal

2.1 Duty to carry out assessment of need

Local authorities have a duty to carry out an assessment of need for community care services, summarised as follows:

Under the NHS & Community Care Act 1990 - Section 47(1) if the assessment identifies the person as being disabled the local authority is required to decide as to the services required under the Disabled Persons (Services and Consultation and Representation) Act 1986 - Section 4.

Under the Chronically Sick & Disabled Persons Act 1970 Section 2(1) local authorities must assess the needs of people who fall within the National Assistance Act 1948 - Section 29(1) which defines a 'disabled person'.

The Carers & Disabled Children Act 2000 – Section 1 gives carers who are caring for a service user aged 18 or over, the right to an assessment (independent of that of the service user) of their ability to provide, or continue to provide, care.

2.2 Fair Access to Care Services and the Duty To Provide

Once a Community Care Assessment is carried out, councils need to make decisions about whether to provide support or not to individuals. Fair Access to Care Services (FACS) provides councils with an eligibility framework for adult social care to identify whether or not the duty to provide services under the relevant legislation¹ is triggered. The duty on social services to provide or arrange services is triggered only for those people with eligible needs - that is, needs above the threshold for services.

Needs that are identified as eligible needs and which sit within the laws relating to a duty on Social Services to provide services must be met. Those needs, however, can be met in a range of ways.

Personnel

- 3.1 Approximately 50 staff work at Ashlea Hostel and, were the service to close, they would be supported on an individual basis to consider the implications for them and to seek redeployment as appropriate. Service closure may result in compulsory redundancies if not all staff could be redeployed.
- 3.2 The Council has a statutory obligation, under the Trade Union and Labour Relations (Consolidation) Act 1992, to inform staff with a view to engaging them in meaningful consultation and this process would start, running alongside any wider consultation on the 2013/14 budget.

Equalities Impact

- 4.1 The full assessment of the extent and nature of the equalities impact is attached in Appendix 3. The recommendations detailed in the report will mitigate the potential impacts as far as possible, ensuring that for specific arrangements are in place for

¹ National Assistance Act 1948, Chronically Sick and Disabled Person's Act 1970, National Health Services Act 1977, Community Care (Direct Payments) 1996 Act, The Carers and Disabled Children Act 2000.
(Note this list is not exhaustive but covers the relevant legislation in relation to this paper)

each individual and that their impairment, gender, sexuality, age and cultural and religious needs are taken into account in any alternative arrangements.

Health and Safety

- 5.1 The health and safety of customers is paramount in any proposal for service change and these are being, and will continue to be considered on an individual basis as alternative Support Plans are agreed.

Environmental Sustainability

- 6.1 These comments have been included within the Asset Management Comments below.

Asset Management

- 7.1 From an Asset Management perspective the issues regarding the condition of the property, especially the ongoing Legionella problems and the suitability of the premises to deliver a satisfactory service to meet the changing needs of the Council's customers, highlight the need for a different delivery model to be adopted which Ashlea Hostel is not capable of delivering in its current format.
- 7.2 The provision of a discrete unit within an existing facility will need more analysis to identify the most suitable option for this facility
- 7.3 If the decision were to be taken to close Ashlea Hostel the site could be sold to support the Council's capital program. The estimated value of the premises would be in the region of £225,000.

Risk Management

- 8.1 The needs of all those individuals using Ashlea Hostel have been assessed and no one will be left at risk as a result of this proposal. Every family and individual is being supported to identify their specific needs and their preferred way to receive short breaks and the planning process includes a full consideration of any associated risks. A small number of families have, to date, chosen not to engage with this process and this is being managed on an individual basis and any risks to the person concerned will be addressed through the Council's safeguarding procedures.

Corporate objectives and priorities for change

- 9.1 The modernisation of adult social care for people with a learning disability in Derby is taking place within the context of the directorate's overall personalisation programme. The Learning Disability Service Plan 2011/2012 therefore set out a number of strategic objectives that represent a passion about making progress in the way that learning disabled people are supported in Derby. These objectives have at their core the ambition to make Derby a city for all – including people with a learning disability.

- 9.2 Because of the impact that personalised support has on people's lives, we can fully expect outcomes to be better and this national evidence is now supported by the local Personal Outcomes Evaluation Tool (POET) survey that showed local people reporting improvements such as increased dignity and independence.
- 9.3 The vision of the **Derby Plan 2011 – 2026** (Derby City Partnership is:
Derby – passionate about progress
The vision of the **Council Plan 2011 - 2014** is:
“To create a city for all, through strong leadership and excellent customer-focused services”
- 9.4 The Adults, Health & Housing Directorate's vision includes commitments that by 2014 Adults, Health and Housing will:
- Continue to protect vulnerable people from harm
 - Further support people to live independently in the community
 - Deliver cost effective sustainable outcomes for people seeking housing and social care support
 - Maximise Choice and Control through Personal Budgets
- 9.5 **Adult Social Care Outcome Framework** includes the national indicator:
ASCOF 1C (NI 130) - Social care clients receiving Self Directed Support (Direct payments and individual budgets)

CASE STUDIES

Fiona uses a Shared Lives carer for her short breaks and states:

“Having my Personal Budget is the first time I have had any help to do what I really want to do. I am going out more and doing lots of different things... On Wednesday I go to my Shared Lives carers. The reason I like going there is that their cats are lovely... and they make me laugh and smile. My mum needs to have a break too and go on holiday and see her friends.” Fiona’s mum says “I am reassured that Fiona is now getting the support she needs. After being widowed two years’ ago I can get out more and start my life again.”

Andrew is looking to go away some weekends with his friends and share support.

People can ‘pool’ their Personal Budgets and share support with friends. Andrew and his two friends are planning to have a regular mini hotel break somewhere different with a support worker. They are getting support to plan this and to find cheap hotel deals. They are excited about having a regular mini-break and visiting new places and it will also give their families a break from their caring role.

James has profound and multiple disabilities and his parents use a personal budget

to arrange a break for them and provide James with a positive experience too. They have a mixture of support that gives them a break. One evening a week they visit their daughter and also see their grandchildren. While they are away, a male support worker from a local charity who has an excellent relationship with James comes into the home and spends time with him. Sometimes they go out for the evening and meet other friends at the local pub where the cook knows James and liquidises food for him. James enjoys the atmosphere. If his health isn’t up to it, they might stay at home and listen to music or do something restful.

James often has seizures during the night and this causes his parents many sleepless nights. To ensure they have a good night’s sleep regularly, they have decided to ask a Shared Lives carer who sometimes supports James during the day, to stay at their house and care for James during the night. About three times a year, they have a long weekend away to give them a break and to spend quality time with James during the day. One of James’ support workers from the charity accompany him for these breaks and supports him during the night and provides some of the care tasks during the day. This provides his parents with the break they feel they need and they are confident that the carers they have chosen from the charity and from Shared Lives know James’ needs and have a strong positive relationship with him which he responds to by laughing and smiling when he is with them.

James’ parents pay £80 per night for a Shared Lives carer to stay at their house 26 nights a year (£2,080) and they pay £14 per hour for a support worker to visit James at their home each week (£2,800). Support during the long weekend breaks cost £1200 on average for each break. In addition James has a variety of daytime support activities and the long term plan is for him to have his own home in the future, retaining the input of the people he has got to know in his circle of support.

Appendix 4 – consultation analysis

Background

Many adults with a learning disability live at home with their families and a vital way of supporting those family carers to continue in their caring role is to offer them a break, meaning the person is supported by someone else and has a positive experience of that break too.

Built in 1978, Ashlea Hostel has offered residential short breaks, originally operating with 22 bedrooms. Numbers have declined since then and increasingly is primarily used by people with complex behavioural and/or healthcare needs, thus reducing the number of rooms in use at any one time. Approximately 60 people still use the service and about half of those are actively pursuing alternatives at present.

The proposal that has been consulted on has been to close Ashlea Hostel and offer people an amount of resource, a Personal Budget, with which they can arrange a break that is tailored to their needs, more socially inclusive and not necessarily in registered residential accommodation.

In the budget consultation that took place in Autumn 2011 the Council made the proposal to release £270000 in revenue over two years as a result of the closure of Ashlea Hostel. Personal budget allocations of social care funding do not assume that everyone will purchase residential care for short breaks. Those that are likely to choose this option are people with profound and multiple disabilities and therefore are potentially entitled to healthcare resources.

Methodology

The consultation needed to capture the views of people who use Ashlea Hostel, customers and family carers as well as the staff who worked there. To be representative it also needed to know what people who didn't use Ashlea Hostel thought about the proposals – people who were having short breaks in other ways and staff and carers who were supporting this to happen.

It was expected that hard copy questionnaires would be the most popular format for capturing information and therefore these were sent to every family carer whose relative uses Ashlea Hostel. Easy read questionnaires were developed in order to capture the views of people with a learning disability and were sent to not only the current Ashlea Hostel users but also those supported in other ways and known to the Learning Disability Services. Whilst it is acknowledged that many people with a cognitive impairment would find the issues and questions complex, every effort was made to capture some simple information about how people might want to spend their time on a short break. Additional independent peer advocacy support was offered people in explaining the issues and in completing these questionnaires.

Notes taken during eight small group meetings facilitated by the advocacy group were received and used as part of the consultation analysis, as too were notes from four meetings Council officers attended with family carers. These, along with the content of emails and letters sent to Council officers and Councillors were analysed to capture the key messages.

Overall findings from the survey

In total 260 questionnaires were received, comprising 116 easy read questionnaires and 144 general questionnaires (of which 24 were completed online). It should be noted that not all respondents answered all of the survey. The total number of responses is therefore shown throughout the report. Some of the responses have been grouped together so that it can be shown the trend of responses people gave. The analysis separates the easy read and general questionnaires but groups the responses from each under the same questions so that the pattern of responses to particular questions can be shown together.

100. **In response to what extent respondents agreed with the statement “Ashlea Hostel should close” and whether people should have choice in how they get a short break**

Fig 1 below shows that 68 respondents (52%) using the easy read questionnaire felt that Ashlea Hostel should not close. Of those, 58% also stated that they should have a choice in how they get a short break. 99 people using the easy read questionnaires (85%) felt they should have a choice in how they get a short break.

Fig. 1 Easy Read Questionnaires – responses to whether Ashlea Hostel should close and whether they felt they should have a choice in how they get a short break.

			I should have a choice of how I get a short break			Total
			I agree	Not sure	Disagree	
The Ashlea Hostel should close	I agree	Count	13	3	0	16
		% within I should have a choice of how I get a short break	13%	19%	0%	14%
	Not sure	Count	29	3	0	32
		% within I should have a choice of how I get a short break	29%	19%	0%	28%
	Disagree	Count	57	10	1	68
		% within I should have a choice of how I get a short break	58%	63%	100 %	59%
Total		Count	99	16	1	116
		% within I should have a choice of how I get a short break	100%	100 %	100 %	100 %

Comments about why people felt this way included:

From people with a learning disability:

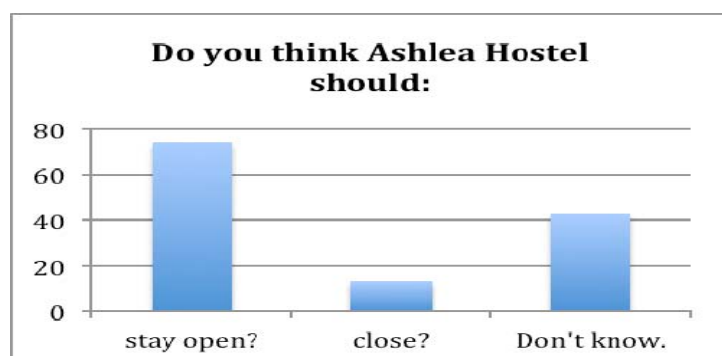
- *I used to go there and it was nice.*
- *Because I don't want to go there*
- *I've been going there for ages and ages and want it to stay open.*
- *I have never been and never been offered it*
- *Because of my learning disability I find it hard to accept change and Ashlea has been my second home for the last 21 years. It is the one place I look forward to going for my short breaks.*
- *It's going to be different.*
- *I don't like Ashlea. I had to go there when my Mum died.*
- *I'm happy it's closing*
- *I want it to close.*
- *I think it might be an experience to go somewhere new.*
- *I go to Ashlea, but would like to try Shared Lives.*
- *I don't care, I go to a hotel with my Mum.*
- *I 'm sad that it's closing.*
- *I had to go there when my Mum was in hospital and when she died, I never want to go there again.*
- *I want it to stay open. I want the Council to stop closing places and put money into them.*
- *Close it if you want to*
- *I don't know, I go to a family for respite.*
- *A lot of people don't like going there*
- *I've been going there for ages and ages and I want it to stay open*

Fig. 2 shows responses to the same questions in the general questionnaire. In total, 73 respondents (57%) indicated that Ashlea Hostel should stay open. Of those, 63, (86%) agreed or strongly agreed that people should have a range of choices in how they take their short break. A total of 113 people (88% of respondents) using the general questionnaire agreed or strongly agreed that people should have a range of choices in how they take their short break. (see Fig.3)

Fig. 2 General Questionnaires – responses to whether Ashlea Hostel should close and whether they felt people with a learning disability should have a choice in how they get a short break.

			People with learning disability should have a range of choices in how they take their short break.						Total
			Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	
Do you think the Ashlea Hostel should ...	stay open?	Count % within have a range of choices in how they take their short break.	43 52.4%	20 64.5%	8 80.0%	0 .0%	1 100.0%	1 33.3%	73 57.0%
	close?	Count % within should have a range of choices	9 11.0%	2 6.5%	1 10.0%	1 100.0%	0 .0%	0 .0%	13 10.2%
	Don't know	Count % within should have a range of choices.	30 36.6%	9 29.0%	1 10.0%	0 .0%	0 .0%	2 66.7%	42 32.8%
Total		Count % within should have a range of choices.	82 100.0%	31 100.0%	10 100.0%	1 100.0%	1 100.0%	3 100.0%	128 100.0%

Fig. 3 General Questionnaires – responses to whether should have a choice in how they get a short break.



Related comments from family carers whose relatives stay at Ashlea Hostel

- Ashlea is a friendly, safe and homely environment with nice staff
- There needs to be choice and Ashlea is one of the choices. As a carer I do not need any further pressure to manage budgets, vetting people and places. Ashlea is a stable environment which is reliable.
- The short break at Ashlea enables us to keep going.
- When my son is at Ashlea I have peace of mind and know he is happy
- The care people get is second to none. Carers need a break to recharge their batteries to do their job.
- Ashlea is a great place if the Council would let it, not like everything they touch is closing down

- *We don't want [our daughter] open to abuse. We don't trust the Council to 'vet' these people who all of a sudden want to foster.*
- *We feel it's suitable for [our son] in every way*
- *I think it should stay open because it gives me a break and our daughter a break with her friends*
- *It gives us as parents time to relax and maybe have a little life now and again. The everyday stresses of caring takes it all and Ashlea comes to our aid.*
- *I feel Ashlea should stay open because we need places for our children with learning difficulties to go as there is not enough places for them. Ashlea has been very good for my son and they are there for an emergency. Also he likes going there as he has friends who he only sees when he is at Ashlea. It would be disastrous if it were to close. All the staff are sweet.*
- *Nowhere else in Derby that is suitable at short notice. We can plan our life around bookings.*
- *Because lots of people enjoy going there and the staff are very helpful*
- *without the respite I don't think it would be long before our daughter would end up in full time care as it is hard enough coping now. We don't want that and I am sure she doesn't either. We have not had a break or a holiday of more than 2 days at a time in years. We are always feeling very tired and stressed as it is please don't make it worse.*

Comments from other respondents included:

- *We provide an excellent service and we have not got enough bedrooms equipment to the referral (sic). If we had it would be running better.*
- *It depends if it is being utilised enough*
- *At this moment it is the only viable option for complex needs. It supports people who use over-sized wheelchairs. Though Ashlea may not be perfect it is still, in my view, the only option that is suitable. People who have complex autistic behaviour may struggle to find a placement in the community.*
- *To release resources and increase choices for people with a learning disability*
- *The Council have a duty of care to provide for adults with disabilities. Until something else is ready to cater for this needed service the centre must remain open.*
- *Appears the council is more interested in saving money. City Council has a duty of care to look after those who cannot fend for themselves. It appears the consultation is just lip service already made your minds up. SHAME ON YOU.*
- *This is the only Council or even private respite service which is so very important to so many citizens of Derby. Without Ashlea the Council would over time need to spend more on long term placements as without Ashlea families would not be able to carry on supporting their children. Ashlea is a safe environment with very high standards and CQC have not said it is not fit for purpose. Who made this statement – what do they know about care standards?*
- *You would be putting staff out of work that are fully trained to work there. Again the staff relate to the service users.*
- *It's old, it's in a bad location, no garden, all that's there are two big screen TVs. I don't think it's right that people of all needs are put together in an 'institution' on the side of a road in Alvaston. I'm surprised it's still open.*
- *People with Profound and Multiple Learning Disabilities need appropriate short break opportunities. At present, many people do not use Ashlea, because they do not want/like the service available there. The Council should consult specifically with customers and carers who do not use Ashlea, as well as those who do.*

2. Responses to whether people should be able to use a range of leisure and community based activities

People with a learning disability were asked, in general, what sort of short breaks they would like and where they would like to go.

Responses included:

- *I come here [Ashlea] every weekend. I'd like to go out and do something different. I like going to cafes and shopping in town. I'd like to go on the train to Nottingham and London. I'd like staff to come with me. I'm not keen on Shared Lives.*
- *I'd like to go to Disneyland for a special break*
- *I'd like to go to Skegness. I went there years ago and would like to go again. I don't want to go in a group. I want to go with one other person. I don't know what else to say because I've never thought about things like this.*
- *I would like to stay in a hotel. I'd like to go in a group.*
- *Go camping*
- *I would like to have a choice where I go*
- *I like spending time with my sister*
- *I don't care. I go to a hotel with my mum*
- *I would like to go to a chalet on the beach in Devon that has wheelchair access*
- *North Wales to go walking*
- *Doing activities like karaoke, bingo, swimming, bowling and socializing*
- *I haven't thought about it. No one has ever asked me this. I need to think about it.*

The survey asked in general about how respondents felt people with a learning disability should be supported to have short breaks: the range of choices, the use of community based support, having choice over who they were with and using their personal budget to pay for it. In total 86.4% of respondents agreed or strongly agreed that people with a learning disability should be able to have a short break which includes a range of leisure and community based activities. Of these, 52.8% (62 people) also felt that Ashlea Hostel should stay open. Fig 4 shows the responses.

Fig.5 shows responses to the whether respondents felt that people should have choice in who they are supported by and who they spend their time with. 91.4% of respondents stated that they agreed or strongly agreed.

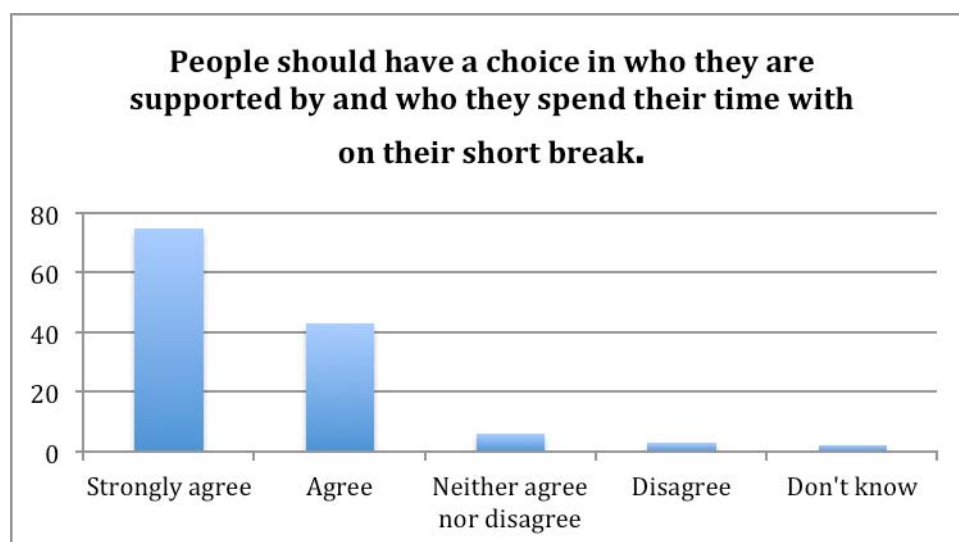
Other comments received relating to this question from the general survey are shown below.

- *I think the hotel idea is dreadful for both the disabled person and the hotel guests. My son needs a familiar safe environment. This questionnaire is very heavily biased against Ashlea which really makes me think decisions have already been made.*
- *People need to have a safe and familiar place to stay with people they can associate with, e.g. other disabilities*
- *In this day and age more suitable options are available such as "shared lives" scheme etc. People with learning disabilities should not be excluded from living and functioning in the community.*

Fig. 4. General Questionnaires – responses to whether Ashlea Hostel should close and whether they felt people with a learning disability should be able to have a short break which includes a range of leisure and community based activities

			be able to have a short break which includes a range of leisure and community based activities.						Total
			Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	
Do you think the Ashlea Hostel should...	stay open?	Count % within be able to have a short break which includes a range of leisure and community based activities.	40 54.8%	22 62.9%	5 62.5%	2 50.0%	0 .0%	3 75.0%	72 57.6%
	close?	Count % within be able to have a short break which includes a range of leisure and community based activities.	8 11.0%	2 5.7%	0 .0%	2 50.0%	0 .0%	0 .0%	12 9.6%
	Don't know.	Count % within be able to have a short break which includes a range of leisure and community based activities.	25 34.2%	11 31.4%	3 37.5%	0 .0%	1 100.0%	1 25.0%	41 32.8%
Total		Count % within be able to have a short break which includes a range of leisure and community based activities.	73 100.0%	35 100.0%	8 100.0%	4 100.0%	1 100.0%	4 100.0%	125 100.0%

Fig. 5 General Questionnaires – responses to whether people should have a choice in who they are supported by and who they spend their time with



3. Suitability of Ashlea Hostel for people with complex needs and whether the Council should ensure overnight residential accommodation is available for adults with profound and multiple learning disabilities.

Asked whether they agreed with the statement that Ashlea Hostel may not be suitable for everyone, 40 people with a learning disability (35%) stated that they agreed and 45 (40%) weren't sure. Of the 64 people who indicated that Ashlea Hostel should not close 19 (48%) indicated that they felt it may not be suitable for everyone.

Fig. 7. Easy Read Questionnaires – responses to whether Ashlea Hostel should close and whether respondents felt Ashlea Hostel was suitable for everyone

			The Ashlea Hostel may not be suitable for everyone			Total
			I agree	Not sure	Disagree	
The Ashlea Hostel should close	I agree	Count	10	2	4	16
		% within The Ashlea Hostel may not be suitable for everyone	25%	4%	15%	14%
	Not sure	Count	11	20	1	32
		% within The Ashlea Hostel may not be suitable for everyone	28%	44%	4%	29%
	Disagree	Count	19	23	22	64
		% within The Ashlea Hostel may not be suitable for everyone	48%	51%	81%	57%
Total		Count	40	45	27	112
		% within The Ashlea Hostel may not be suitable for everyone	100%	100%	100%	100%

Asked about the suitability of Ashlea Hostel for people with complex needs 46.6% (55) people using the general questionnaire stated that they felt it was 'suitable' or 'very suitable'. 36.4% (43 people) stated they didn't know.

Asked whether they agreed or disagreed that the Council should ensure overnight residential accommodation is available for adults with profound and multiple learning disabilities, 114 people (91.2%) stated that they agreed or strongly agreed.

As illustrated in Fig.5, of these 114, 60 people (66%) stated that they felt Ashlea Hostel was suitable or very suitable for people with complex needs.

Comments included:

- *Because there are people who are not as independent as me and cannot go on a holiday as I can. They need lots of help.*
- *Building too large and no longer suitable. A more appropriate smaller building is required with the appropriate equipment.*
- *Overnight respite is needed but a better building with higher staffing and more individualised support is needed*
- *Unsuitable building, too costly to maintain and run*
- *If not Ashlea then a smaller place that wouldn't cost as much to run and would be full.*
- *Facilities are good and ideal for coping with certain disabilities. Some individuals will be very vulnerable in normal surroundings.*
- *A vast amount of money has been invested in the property to upgrade standards. Location and easy access. Staff have put a lot of time into keeping environment outside up to a high standard.*
- *Derbyshire has lots of Council run services. Why are we creating a postcode lottery?*
- *Put the money into council services and you will get good, very good services. If not then you will let people with learning difficulties down and we will have a poor and second rate service*

- Whilst Personalisation suits the needs of a number of people with special needs, there will always be a need for specialised units for those with complex needs. Providing a familiar place for them to stay whilst their carers recharge their batteries.
- The proposal of another building with better facilities to be found for people with multiple disabilities, which Ashlea have and qualified staff which are fully trained would be cheaper to modernise. Ashlea ground floor and rent top rooms out for other purposes i.e meeting rooms and we already have assessment unit up and running, where would emergency admissions go at one minute notice when Ashlea has gone?
- A variety of options should be available. People should have real choice and this includes a residential home that is properly run and staffed with people that have the right skills. Shared lives will be suitable for some people but not for young adults with challenging behaviour. They need people with the right skills and experience and an appropriate setting. Adults with profound and multiple disabilities need accommodation that can meet their needs, and continuity of staff with the correct skills so that carers can have a break with confidence. This allows them to continue to care for their loved ones and saves Derby City Council the cost of full time care. It is false economy to provide anything less.

Fig. 7. General Questionnaires – responses to whether respondents agreed or disagreed that the Council should ensure overnight residential accommodation is available for people with people with profound and multiple disabilities and, of those, how suitable respondents think Ashlea is for people with complex disabilities.

			How suitable or unsuitable do you think the Ashlea Hostel is for people with complex disabilities						Total
			Very suitable	Suitable	Neither suitable nor unsuitable	Unsuitable	Very unsuitable	Don't know	
How much do you agree or disagree that the Council should ensure overnight residential accommodation is available for people with PMLD	Strongly agree	Count	37	12	5	6	3	28	91
		% within How suitable or unsuitable	92.5%	54.5%	62.5%	85.7%	75.0%	63.6%	72.8%
	Agree	Count	3	8	1	1	1	9	23
		% within How suitable or unsuitable	7.5%	36.4%	12.5%	14.3%	25.0%	20.5%	18.4%
	Neither agree nor disagree	Count	0	1	2	0	0	3	6
		% within How suitable or unsuitable	.0%	4.5%	25.0%	.0%	.0%	6.8%	4.8%
	Disagree	Count	0	1	0	0	0	0	1
		% within How suitable or unsuitable	.0%	4.5%	.0%	.0%	.0%	.0%	.8%
	Don't know	Count	0	0	0	0	0	4	4
		% within How suitable or unsuitable	.0%	.0%	.0%	.0%	.0%	9.1%	3.2%
Total		Count	40	22	8	7	4	44	125
		% within How suitable or unsuitable	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

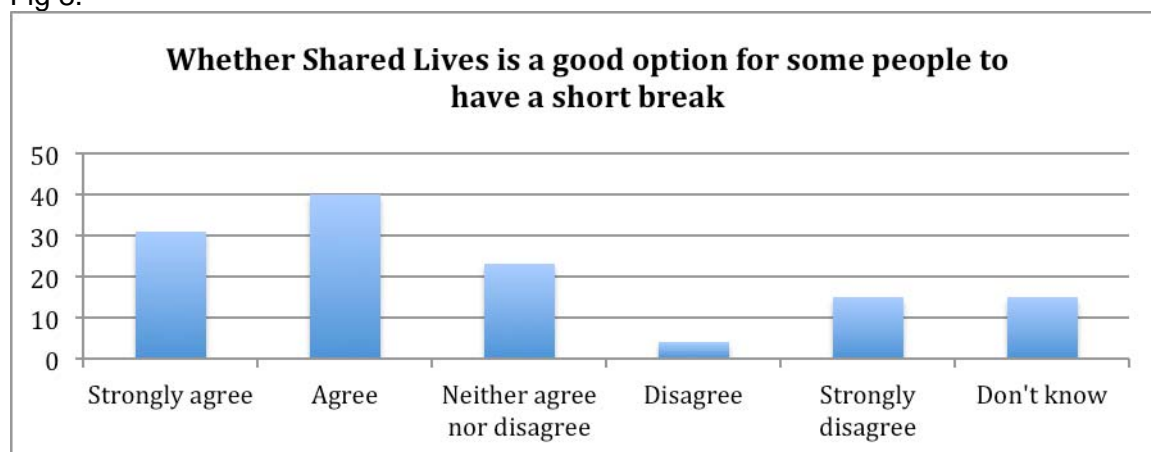
4. Whether or not Shared Lives is a good option for some people to have a short break.

Asked to what extent they agreed or disagreed that Shared Lives is a good option for some people to have a short break, 55% of respondents (71 people) using the general questionnaire stated that they agreed or strongly agreed (see Fig 8).

Comments received relating to Shared Lives included:

- *Identify how to attract carers into the Shared Lives. Current allowances need to be reassessed to provide incentives for joining this.*
- *Allowances need increasing for "Shared Lives".*
- *I will not use Shared Lives Scheme for my daughter even if it means I get no respite.*
- *Shared Lives allows me to have experiences in a safe environment that are individual to my needs.*
- *The shared lives scheme will not suit someone like my son who can be difficult and aggressive.*
- *Ashlea is a lifeline for us. Our daughter loves going there. She needs a break from us and we need a break from her. We need a place like Ashlea as our daughter's needs are very high. Shared Lives and hotels would never be any good for someone with such high needs.*

Fig 8.



5. Makeup of respondents using the general questionnaire.

- 85% of respondents were White and British. The second highest ethnic group was Asian or Asian British – Indian (6 respondents)
- Of the 113 responding, 48 (42.5%) stated that they consider themselves to be a disabled person.
- 67% of respondents were female and 33% were male
- 27 of the 39 family carers who responded to the question stated that their relative had last had a short break at Ashlea Hostel. 8 respondents had used Shared Lives or had organized a break themselves.
- Age range of respondents is shown below.

