

# **Respite care for people with physical disabilities in Hampshire**

## **Responses to the consultation 13 July – 4 September 2015**

# Respite care for people with physical disabilities in Hampshire: responses to the consultation

## *Executive summary*

The 'Respite care for people with physical disabilities in Hampshire consultation' sought the views of stakeholders and the general public on the proposal to close the physical disability respite service at John Darling Mall in Eastleigh.

The consultation was launched on 13 July and closed on 4 September 2015. Responses received up to 7 September have been taken into account in this report.

A wide range of stakeholders were informed about the consultation, including service users, John Darling Mall staff, local politicians, local disability forums, the Princess Royal Trust for Carers and other voluntary and community groups and organisations. Stonewater Housing Association leases six independent living flats that are an integral part of the John Darling Mall complex. Should the decision to close the respite service be made, the Council would propose to develop the whole site for Extra Care Housing, thus there could be a further impact upon the tenants of the flats. Hence the views of the tenants were also sought.

The consultation questionnaire was given ethical approval by Hampshire's Research Development and Governance Panel. It was published online on Survey Monkey via dedicated web pages, and copies of the questionnaire were made available in paper and alternative formats, such as Large Print. Paper copies of the consultation questionnaire were sent to service users.

Feedback to the consultation was also accepted in the form of letters and emails.

Five consultation events took place with service users and their families. An independent advocate was available at each event to support attendees in responding to the consultation.

## **Responses**

- 102 people submitted a consultation questionnaire.
- 100 people completed the first question in the questionnaire. 70% were against closing the service, with the majority, 53%, describing their attitude as 'strongly against'. 14% were in favour of the proposals, 4% of whom described their attitude as 'strongly in favour'. 13% were neither in favour nor against the proposals.
  - 36 people who responded to the consultation described themselves as users of the respite service at John Darling Mall. Almost 70% of respondents who used John Darling Mall for

respite (24 people) were against the proposal, with 14% (five people) in favour. Just under half of the respondents (49%, 17 people) were strongly against the proposal, with only 6% (2 people) strongly in favour. 17% (six people) were neither in favour nor against the proposal.

- 21 people who responded described themselves as the family member or carer of somebody who uses John Darling Mall for respite. 90% of them were against the proposal with none in favour.
- Of the six tenants of Stonewater Housing who responded, three were strongly against the proposal, one was neither for nor against, and two were in favour (with one of the two being strongly in favour).
- 89 people expressed a view on which alternative respite services the Council should be able to offer to people who currently access respite at John Darling Mall. The most frequent choice was for building-based respite provision for adults, with 54% (48 people) ticking this option.
  - Extra Care housing was the second most popular choice, chosen by 38% (34 people).
  - Accessible holidays were chosen by 36% (32 people).
  - 28% of respondents (25 people) chose Carer Replacement Services.
  - 17% (15 people) chose Shared Lives, a scheme where the service users goes to stay with a family or individual in the family or individual's home.
  - 25% of respondents (22 people) chose 'Other', with eight of these people saying John Darling Mall should be retained.
- 2 letters and emails were received. They were both against the proposals and criticised the alternative services proposed for respite.

### **Key themes (points most commonly made) from questionnaire answers, letters and emails**

- Many people said they did not want John Darling Mall to close because it meets the needs of service users and carers: people value it and feel closing it may mean their needs will not be met.
- Many considered the service to be of high quality, with some service users saying they enjoy it or love it there and carers saying they can relax knowing that the people they care for are well looked after and safe there. Many people said they would be upset if the service closed or that the Council should consider the emotional impact of closing the service on the service users, their families, the staff and the tenants. Some said the staff are good or excellent. Some people highlighted that the staff understand the needs of users and it would be very difficult for some service users, especially those with complex needs, to accept a new

respite place or go through the process of having to get used to a new place and different staff.

- People said there is a dearth of other services for people with physical disabilities. They stressed that there is a need for services that are for people with physical disabilities only. Some were concerned that with alternative services they would not be able to book respite in advance. Many people expressed a preference for buildings-based services and valued the communal setting for its potential to enable people to socialise.
- There was a strong view that the proposed alternatives to John Darling Mall for respite would be unsuitable. Many said it would be inappropriate for people with physical disabilities to mix with people with learning disabilities, older people or people with Alzheimer's or dementia. There was a fear that people would not get the mental stimulation they need with those service users. Some people said accessible holidays would be very desirable and meet their needs, but that they are unaffordable - some had requested accessible holidays but as the Council would not fully fund the holiday they could not afford to go. There was concern that some of the alternative options - Shared Lives, Carer Replacement Services and Extra Care housing - would not enable people to socialise with peers. There was concern that buildings-based alternatives would be too far away for people to maintain local friendships and ties (e.g. having friends visit them there, or going to day service and seeing friends there).
- There was some concern that tenants would be made to leave their home if the proposal was accepted and three tenants said they did not want to leave their home.
- A small number of people commented in favour of the proposal, including some service users and two tenants, citing experiences of poor service at John Darling Mall that did not maximise their independence and choice, and discomfort in the building.
- Respondents suggested a range of alternative options to the proposals. These included: keeping John Darling Mall open; replacing John Darling Mall with another buildings-based respite centre on site or elsewhere for people with physical disabilities; moving it to a smaller building; refurbishing or improving John Darling Mall; converting it into housing for disabled people; close an alternative service; or save money elsewhere.

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## ***Introduction***

The 'Respite care for people with physical disabilities in Hampshire consultation' sought the views of stakeholders and the general public on the proposal to close the physical disability respite service at John Darling Mall in Eastleigh.

## ***How the consultation was undertaken***

The consultation was launched on 13 July and closed on 4 September 2015. Responses received up to 7 September have been taken into account in this report.

A wide range of stakeholders were informed about the consultation, including service users, John Darling Mall staff, local politicians, local disability forums, the Princess Royal Trust for Carers and other voluntary and community groups and organisations. Stonewater Housing Association leases six independent living flats that are an integral part of the John Darling Mall complex. Should the decision to close the respite service be made, the Council would propose to develop the whole site for Extra Care Housing, thus there could be a further impact upon the tenants of the flats. Hence the views of the tenants were also sought.

The consultation questionnaire was given ethical approval by Hampshire's Research Development and Governance Panel. It was published online on Survey Monkey via dedicated web pages, and copies of the questionnaire were made available in paper and alternative formats, such as Large Print. Paper copies of the consultation questionnaire were sent to service users.

Feedback to the consultation was also accepted in the form of letters and emails. Five consultation events took place with service users and their families.

- Thursday 30 July, Fareham Library, 2.30-6.30pm
- Tuesday 4 August, Farnborough Library, 9.30am – 12.30pm.
- Monday 10 August, Basingstoke Discovery Centre, 1.30 – 5.30pm.
- Tuesday 18 August, Lymington Library, 2.30 – 6.30pm.
- Wednesday 26 August, Wells Place Centre Eastleigh, 1.30 – 4.30pm.

The details of the events were sent out to service users with paper copies of the consultation questionnaire. Hampshire County Council telephoned each service user and spoke to them or a family member to see if they wanted to come to an event and then booked them onto it. An independent advocate was available at each event to support attendees in responding to the consultation.

After 7 September, all of the consultation responses received were collated and analysed by the Adult Services Research Manager, a trained researcher who works to promote the rights, safety, dignity and wellbeing of service users and carers and is unconnected to respite services.<sup>1</sup> People's comments were analysed using 'content analysis'.<sup>2</sup> This involved identifying manifest themes (overt messages) using the inductive method (i.e. themes were drawn by looking at what people said).<sup>3</sup> Latent (i.e. underlying) themes were not analysed as this would have involved a lot of interpretation by the researcher and could have resulted in people's points being misconstrued.

### ***Who responded to the consultation?***

- 102 people submitted a consultation questionnaire. Some were from organisations, including voluntary organisations. 36 people who responded said they used John Darling Mall for respite. 21 people identified themselves as family members or carers of someone who uses John Darling Mall for respite. Six were tenants of Stonewater Housing. More details about questionnaire respondents can be found below under the chapters for Questions 2 and 3 and Section 3 of the questionnaire.
- A letter and an email were received from two individuals, both physically disabled people, with one identifying themselves as a user of the service. Both criticised the suggested alternatives for respite care and praised the service and social networks offered by John Darling Mall. More details can be found below under 'What people told us: letter and email'.

### ***What people told us: understanding the results***

Please note that where numbers of people who made a particular comment are given, they should be treated with caution: quantifying people's views necessitates a degree of interpretation. Furthermore a few respondents seem to have made more than one consultation response, in which case their point might be recorded as the view of more than one respondent. Nonetheless the numbers have been included where they may perhaps usefully give some indication of commonality of feeling amongst respondents. This is important because answers to the 'tick box' questions do not give the full picture regarding people's views.

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<sup>1</sup> Rachel Dittrich, member of the national Social Care Research Ethics Committee  
<http://www.srec.org.uk/index.asp>.

<sup>2</sup> For some brief information on content analysis see  
[http://researchskills.epigeum.com/courses/53/course\\_files/html/course\\_files/qualitative\\_6\\_3.html](http://researchskills.epigeum.com/courses/53/course_files/html/course_files/qualitative_6_3.html)  
or [http://www.psychology.soton.ac.uk/researchmethods/lectures/media/2007-10-29/qual\\_lecture3.ppt](http://www.psychology.soton.ac.uk/researchmethods/lectures/media/2007-10-29/qual_lecture3.ppt).

<sup>3</sup> For a brief description of the inductive method, see  
<http://www.socialresearchmethods.net/kb/dedind.php>.

## What people told us: questionnaire responses

### Section 1: The proposed service closure

#### Question 1.

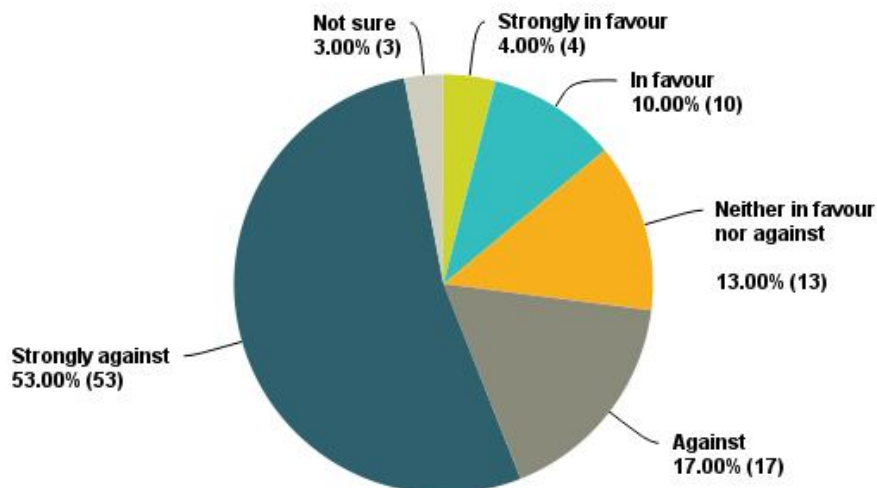
The County Council is proposing to close the physical disability respite service offered at John Darling Mall in Eastleigh. How would you describe your attitude to this proposal?

100 people completed the first question in the questionnaire.

- 70% were against closing the service, with the majority, 53%, describing their attitude as 'strongly against'. 14% were in favour of the proposals, 4% of whom described their attitude as 'strongly in favour'. 13% were neither in favour nor against the proposals.

#### Q1 How would you describe your attitude to this proposal?

Answered: 100 Skipped: 2



- Almost 70% of respondents who used John Darling Mall for respite (24 people) were against the proposal, with 14% (five people) in favour. Just under half of the respondents (49%, 17 people) were strongly against the proposal, with only 6% (2 people) strongly in favour. 17% (six people) were neither in favour nor against the proposal.

- 90% of people who described themselves as a family member or carer of someone who uses respite at John Darling Mall were against the proposal with none in favour.
- Of the six tenants of Stonewater Housing, three were strongly against the proposal, one was neither for nor against, and two were in favour (with one of the two being strongly in favour).

76 people gave reasons for their answer choice. The key themes (most frequently made comments) from people's answer choices were as follows.

### Comments against the proposal

- The most common reason given by those against the proposed closure was that John Darling Mall meets the needs of its users and/or their carers (40 people): they value it, are happy or love it there, and closing it would mean their needs are not met.

*"Myself and my wife found it invaluable as she was able to have a break from caring for me."*

*"The facilities meet my needs as I am able to occupy my time without much need for assistance, but when I do need help I know it is just a button press away."*

*"I have been confident that he is being cared for and I can relax."*

*"My family are also very satisfied with the way I am looked after during my stays."*

15 respondents said that closure would have a negative impact on service users who enjoy it there, and on the carers. People said carers can get a proper break when the person they care for is at John Darling Mall, knowing the person will be well cared for. Five service users said they love it or enjoy their time at John Darling Mall. Some people said they, or others, would be upset if the service closed, and anxiety over the proposed closure was affecting people's wellbeing.

*"This could have an impact on our state of mind while families and partners are away who will in turn worry about us and we will want to contact them so it is not respite for them or us."*

*"Prior to 2008 my late husband used the respite centre regularly. If the facility wasn't available I would have ended with a mental breakdown."*

*"I go to John Darling Mall every two months. I enjoy it there and would miss it so much. Please don't close it."*

Four people expressed concern about the possibility of having to change to a different respite home and get used to a new place and new people. There was anxiety that it may be difficult to try to get service users with complex needs into a new routine and to try to get new staff to understand their needs.

*"It is very unsettling. I don't like change. I find it very stressful getting used to a new environment and new carers. As my speech is very unclear I worry my needs may not be met if they don't understand me".*

*"Over the 14 years I have been using John Darling Mall I have grown to look upon it as home from home and the staff have become almost family. I would be devastated to have to get used to a new respite home, with staff who do not know me."*

*"My father who is 70+ and has a physical disability and brain damage due to a subarachnoid haemorrhage over 10 years ago is very settled at John Darling Mall and routine and familiarity are important to him. It took a long time for him to be happy going there for respite stays, but now he wouldn't want to be anywhere else."*

- 26 people commented that they were against the proposed closure of John Darling Mall because of the high quality of the service or facility. Seven of the 26 said the service provides independence, rehabilitation and integration. Three of them seemed to be referring to the independent living flats in particular and two appeared to be referring to the rehabilitation service that used to be offered at the site rather than referring to the respite service currently provided.

*"I worked at John Darling Mall in the late 80s... I found John Darling Mall second to none in the care and environment that they provided. The disabled were rehabilitated, integrated into a strong community and live as equals there, which gave them the will and skills to work through their life challenges."*

*"I got a lot out of John Darling Mall. It was my own freedom. I got help if I needed it. It was like living on my own but people around if needed. I felt safe. It was great independence and helped me get ready and prepare for living on my own. It gives people a boost."*

*"This is a vital service for people with disabilities. It helps to give them the opportunity to regain skills to become independent, or maintain their independence when returning to the area. It would be a travesty."*

*"For some it has been their first opportunity of living away from the family home... the independent living flats are invaluable in enabling people to test out their ability to move towards more independent living in the wider community. They are able to learn, experiment, address any potential difficulties they might have, in a safe environment. Additional skills are learnt to address any areas of concern. Independence and confidence is enhanced. To close this facility would be regressive and absolutely against the best interests of those who benefit from the very comprehensive service that John Darling Mall provides."*

13 of the 26 praised the staff, with five of them highlighting that the staff understand their needs or the complex needs of the person they care for.

An additional three people cited 'quality of care' as a reason to be against the closure.

*"The staff are brilliant with [name]'s care needs and are very very friendly."*

*"I would be very upset if the John Darling Mall closes. I agree the building needs a facelift but have always found the place well run."*

*"The building is old but the staff are wonderful. [Name] will be very sad to leave them."*

*"You are removing these people from their carers who know and love them."*

*"The staff know and understand the complex nature of my husband's disability. Moreover he knows the staff, building and routine of John Darling Mall ensuring that his respite does not place undue stress on him."*

Five commented that they, or service users, are safe at John Darling Mall.

*"The mall is partially outdoors (in terms of ventilation) and this provides a dry yet safe way for residents to go outside, safe in the knowledge they will come to no harm."*

Four people praised the design of the building, commenting that having a partly outdoors mall means people can meet and socialise with their peers. Other comments praised the rooms (three people); easy access with facilities all on one level (two people); the food (one person); the outings (one person); the smoking room (one person); and the fact that it was purpose built (one person).

- Another common reason people gave as to why they were against the proposed closure was that there are a dearth of services for people with physical disabilities, few services like John Darling Mall, and this type of buildings-based respite for people with physical disabilities is still needed (17 people). Some said that, as John Darling Mall is the Council's only respite centre for physical disabilities, it should be retained or replaced with a similar service. They felt that it was the only suitable type of respite to meet their needs and give carers a proper break. Some stressed that it was important to have services for people with physical disabilities only. The need to book traditional respite beds in advance was also emphasised.

*"Anecdotally we sense there is a demand and residents have been unable to access this accommodation, being told there is a waiting list. It is not clear why [according the document] there isn't a demand and what kind of respite care people are currently already preferring to John Darling Mall."*

*"It is clear from the Hampshire County Council documentation that there is little provision for those with physical disabilities in Hampshire, whereas there appears to be excess provision for those with learning disabilities, specifically Croft house in Fareham where 'only six beds/rooms are in use'."*

*“Having recently looked into the future care for my daughter, I was very concerned at the lack of choice for the type of care she needs. John Darling Mall is the only type of place that is suitable locally to where we live... it is a blow that it might close.”*

*“Why can’t they build something for people with physical disabilities rather than shove them in with other people?... Somewhere else that could replace it would be good.”*

*“It seems that there is nothing suitable for respite in the New Forest area where I live for people with severe physical disabilities only.”*

*“Resources for people with physical disabilities are practically non-existent.”*

*“Any services for adults with physical disabilities should be prioritised financially.”*

*“If this service is taken away an alternative needs to be put in its place – the alternative being beds that can be booked for respite. Not the ad hoc basis that if a room is empty in a nursing home then it will be available for respite. The demand on unpaid carers is huge and planned away from the home respite is the only time they actually get to switch off and rest from their caring responsibilities.”*

- 17 people also said they were against the proposed closure because the alternative options for respite are unsuitable. They were concerned that alternatives will not meet the needs of service users and people may refuse them. Six of the 17 said it was inappropriate to put people with physical disabilities into respite services designed for people with learning disabilities, with several saying they did not want to mix with people with learning disabilities, and would suffer from lack of no mental stimulation. Similarly some said it would be inappropriate to put people with physical disabilities who are not old into a care home for older people (five people) or in a home with people who have Alzheimer’s or dementia (four people).

*“My husband... has used another care home in Basingstoke and did not get the care that John Darling Mall do. Care home, although smaller than others, let him down and he refused to go back there insisting on going back to JDM... This would set my husband back immensely and he may not want another respite stay which would put pressure on me. Please refurbish.”*

*“Mixing with mentally disabled clients can be quite depressing for those who are not. It is not possible to have stimulating conversations.”*

*“Younger people with learning disabilities are noisy and it’s not suitable.”*

*“While it might be appropriate to accommodate an adult with physical disabilities in a unit usually for learning disabilities, this will not always be the case; effective and sensitive design and refurbishment of existing units is needed.”*

*“John Darling Mall is the only respite centre that meets my needs. I am only 57 and do not wish to spend my respite time in an old folks home!”*

*“My husband is a 59 year old disabled but mentally intelligent male. He is not a young person with mental/physical disabilities, nor an elderly person with dementia. I am not aware of any alternative respite centres that would be suitable for him.”*

Three people said the other plausible alternative options for them are too far away. One said they cannot afford to access a private version of John Darling Mall. One said that Extra Care, Shared Lives and Carer Replacement services would be unsuitable as they do not enable people to mix with their physically disabled peers. One person said accessible holidays are too expensive.

- 12 people said they were against the proposed closure of John Darling Mall because it is in a good location. People variously said that it is local or easily accessible to them (four people), friends and family can visit them there (five people), it is near to the Hexagon so they can still attend day service when they are in respite (three people), it is near to facilities such as the chemist, doctor, café, shops etc. with level access (two people), and it is central to Hampshire (one person).

*“It is near enough to home for them [my family] to come and see me if anything should happen to me.”*

*“I know someone who lives in Eastleigh and he visits me and takes me out. I will miss this interaction.”*

*“Eastleigh is far more central to most of Hampshire than the given alternatives of either Fareham or Basingstoke and provision for those with physical disabilities should be retained in Eastleigh.”*

- Eight people said they were against the proposal to close the service as they felt that the building had been run down deliberately (five people), and/or had the potential to be well used if it was refurbished or had more going on (four people).

*“John Darling Mall should be refurbished to accommodate all age groups with physical disabilities and this in turn would attract 100% utilisation.”*

*“The building does not appear to have been well maintained, which will itself have limited demand.”*

- Five people commented that they were against the propose closure because it would mean tenants living in the flats would have to leave their homes. Three of them were tenants saying they did not want to leave.

*“I certainly think it should stay open. If it closed I would have to leave my home. I’ve lived here for nearly four years.”*

*"It has been my home for a long time and while I don't use the respite/communal areas much, that is because it has been run down so much."*

*"I would have to move out of my home if John Darling Mall closed. I've happily lived here for 20 years. I had no intention of moving. There is no reason for me to move. I like living here. There is everything I need here."*

*"We are very concerned about the five residents, for whom the prospect of an imminent move, away from their home area, family, friends and support networks is causing anxiety and if realised will likely compromise their health and wellbeing. Eastleigh Borough Council is already working with Hampshire County Council to identify suitable new accommodation, but this process cannot be rushed, and residents should be able to stay in John Darling Mall until accommodation is found that is suitable, with Hampshire County Council and Eastleigh Borough Council working in a timely way to achieve this."*

- Two people said that the Council should save money elsewhere rather than closing John Darling Mall. One said the Council wastes money elsewhere and the other said jobs should be cut to pay for refurbishing the service. Another said the Council can afford to pay for refurbishment. Two said the proposal is all about money and the Council is not interested in people or how they feel. One said vulnerable people are easy targets for cuts.

*"I believe Hampshire County Council can save money elsewhere. The vulnerable are easy targets. I am disabled and used to attend day service... then Hampshire County Council decided to save money and close it down, all the wonderful promises the council would help us into other places never came about."*

- Two people felt that insufficient information had been provided about future use of the site. They wanted to know whether homes on the site would be affordable, private sector, or for purchase or rent. One queried whether the model of housing would meet local needs and suggested that, rather than housing, a unit that tackled the need for respite and beds to prevent bed-blocking would be more useful.

*"Proposals for the reuse of John Darling Mall need to be properly tested, sustainable and need to be financially robust, given the changing needs of residents, social care markets and funding models including government welfare regimes. Proper consideration should be given to a flexible unit that could help address local 'bed blocking' pressures (and receive income from Clinical Commissioning Group), and cope with changing levels of demand for respite. A formal undertaking should be made that the building would not be sold for general needs housing."*

- One said other avenues for keeping John Darling Mall have not been considered and staff have not been consulted much over the years about possible avenues. One person said they thought closure was a

foregone conclusion and that the Council would not take any notice of objections to the proposal.

*“John Darling Mall is purpose built and should be up-graded to modern standards. Five million is not a lot of money these days. Much of this could be recouped by getting rid of the non jobs that all County Councils have.”*

### **Comments neither for nor against the proposal**

- Reasons people said they were neither for nor against the proposed closure were:
  - They felt no connection with the staff (one person, a tenant in a Stonewater Housing flat).
  - The person they care for only stayed there once (one person).
  - They were now aware of alternative provision (two people).
  - They were looking forward to the variety of the alternatives (one person).
  - They would be sorry to see it close but understood why it might need to (one person).
  - They were making a neutral response because they are a provider of alternative services.

### **Comments in favour of the proposal**

- Six people said the reason why they were in favour of closure was because they thought the service there was poor. Two individuals and one organisation from the six said the service was outdated and did not maximise independence and choice, or that they were treated like children there. One said the service was boring. One criticised the staff, giving an example of very poor practice that occurred when they needed help with personal care, and another said the staff and service were ‘overly politically correct’.

*“Although valued none [of the three members of our organisation who used John Darling Mall] felt that the service supported choice and control, not did it maximise their independence (old fashioned, felt they were there to be ‘looked after’).”*

*“I believe institutional solutions to be inappropriate to modern personalised service provision. John Darling Mall’s model was already outdated when it was built.”*

*“John Darling Mall no longer offer a great deal in the way of facilities which would appeal to me during a period of respite care. I generally find it boring with nothing to do.”*

- Five people said they were for the proposed closure because of the building. Three of them said the building is poor and uncomfortable to

use, two said it needs modernising and one said they were for closure because it would be expensive to improve the building.

*“The building is too hot in the summer and very cold in winter with snow dropping in the mall, which makes my stay very uncomfortable.”*

*“The building isn’t appropriate for a long stay. It’s raining today and there is water pouring through the roof.”*

*“It needs a major overhaul- almost knocking down and rebuilding. It looks cold, dark and dingy.”*

- Two people, tenants of Stonewater Housing, said they were for the proposed closure as they may get more suitable housing as a result.

*“We live in one of the flats owned by Stonewater and feel John Darling Mall has changed dramatically over nearly 18 years and we have outgrown it.”*

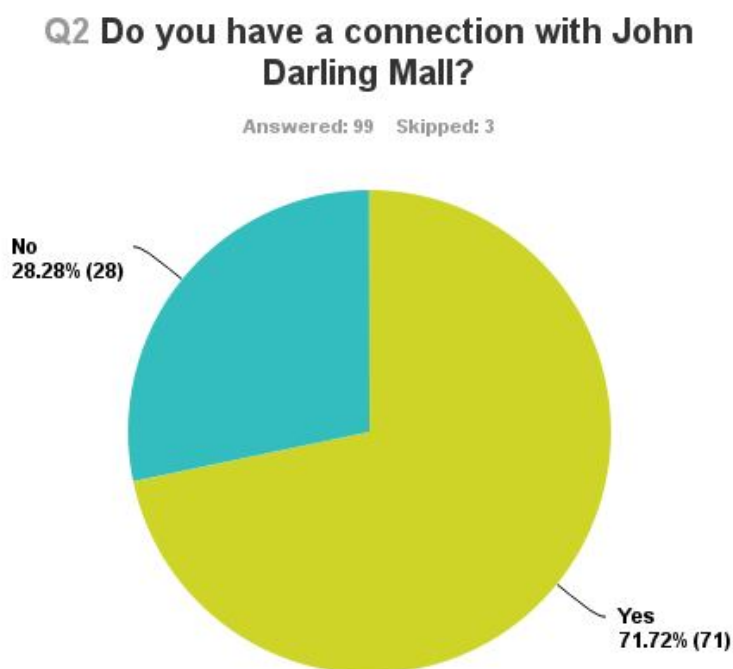
*“I will probably get a better flat now.”*

- One person said they were in favour of the proposed closure because not many people use the service. One said it should be closed but then opened again in a different, modernised form. One said they were in favour of closure but praised the happy environment and caring and supportive staff and suggested that the facilities were adequate for respite.

## Question 2.

### Do you have a connection with John Darling Mall?

99 respondents answered this question. 71 answered 'yes' and 28 answered 'no'.



## Question 3.

### Which of the following best describes your connection?

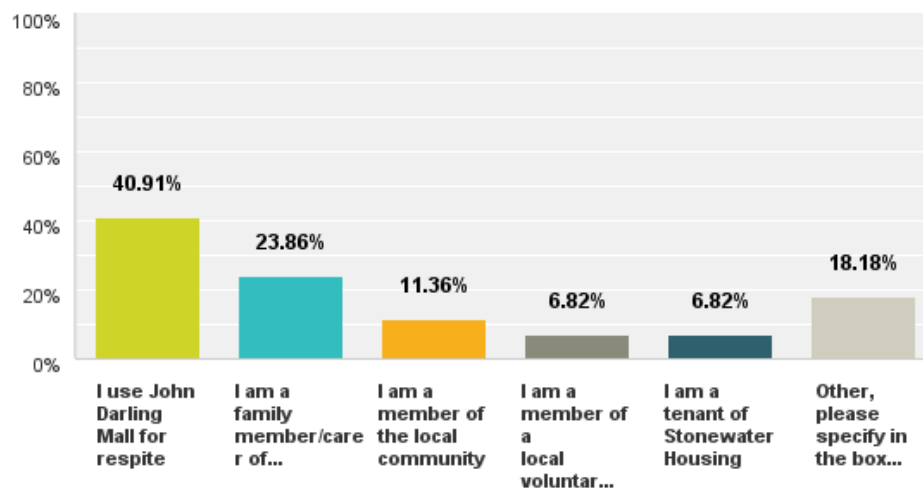
88 people answered this question.

- 36 people (41%) used John Darling Mall for respite.
- 21 (24%) were family members or carers of people who use the service for respite.
- Ten (11%) were members of the local community.
- Six (7%) were tenants of Stonewater Housing.
- Six (7%) were members of a local voluntary or community group.
- Others included a borough council, employees, professionals who had referred people to John Darling Mall, people who used John Darling Mall

in the past, carers of people who used the service in the past, a user-led organisation, family members of Stonewater tenants, an independent advocate, former employees, a respite provider, and a friend of an employee.

### Q3 Which of the following best describes your connection?

Answered: 88 Skipped: 14



#### Question 4.

**If the Council decides to close the service at John Darling Mall, what support or practical assistance would you like to help you find alternative respite provision?**

52 people responded to this question, a mix of users of respite and their family members and carers.

- Six simply answered that they wanted help to find somewhere else.

*“A complete stress-free package. My parents in law who are users of respite are elderly and life is stressful enough without the burden of finding somewhere else.”*

- Others asked for help to find alternatives with specific features as follows:
  - Somewhere the same as John Darling Mall, or with the same or similar quality of care, service and facilities (eight people). Two specified that this needed to be buildings-based respite.

*“A centre that provides exactly the same service. My husband is happy and settled there and loves the people/carers and the food.”*

*“You need to find or make another place like John Darling Mall so we can still get a good standard of care and quality respite when I need it.”*

- Somewhere nearby or easily reachable (seven people). Two of the seven said it must be nearer than Basingstoke and the other buildings-based options mentioned in the consultation document. One said it needs to be near the Hexagon Centre in Eastleigh so they can still attend this day service when at respite.

*“We live in the New Forest and Basingstoke etc. is too far for us to go for the regular respite my husband needs. Without respite neither of us could continue to carry on at home.”*

- With mental stimulation and not with people with mental impairments (five people). One specifically said it should not be with people who have learning disabilities and two said it should not be with people with Alzheimer’s or dementia.

*“Am concerned that some of the alternative homes are for people that have mental health problems.”*

*“I do not want to be placed in a nursing/care home that specialises in dementia care. I was placed at short notice in [name of care home] and had a very bad experience there of the care provided. It was so bad that my husband, who was recovering from an operation, came and collected me several days earlier than planned as he did not feel I was being cared for and in a safe environment.”*

- Not with older people or in a care or nursing home (four people).

*“He does NOT require an Old Person’s nursing home, but a mixture of ages and disability types, where he can have stimulation and conversation. He has used Vitalise at Netley in the past and was always very happy there because of the mix of personnel.”*

- Somewhere with high quality of care, where people will be well looked after (four people).
- Respite for people with physical disabilities only, as their needs are different to people with learning disabilities and older people (three people). One of them expressed the view that staff in homes for people with learning disabilities and older people are not trained to handle people with physical disabilities.
- Somewhere affordable or at the same price (two people).
- Somewhere with activities/more activities (two people).
- Somewhere with staff who know the service user well, so would know what to do in an emergency (one person).

- Somewhere with district nursing available (one person).
  - Somewhere offering help with activities of daily living with as much independence and dignity as possible (one person).
  - Somewhere that the service user would be happy with (one person).
  - Somewhere friendly (one person).
  - Somewhere spacious for a wheelchair (one person).
  - Somewhere with a smoking room (one person).
  - Somewhere where the opportunity to exercise is given (one person).
  - Somewhere with a games room (one person).
  - Somewhere with a nice garden (one person).
  - Somewhere with a mixture of ages and physical disabilities (one person).
  - Respite that is available when needed (one person).
  - Somewhere to go in an emergency or when the carer is away (one person).
  - Respite that is offered by Hampshire County Council in-house (one person).
  - Respite where the service user can stay at home (one person).
  - Care homes to be rated so people can make an informed choice about where to go for respite (one person).
- Three people said the Council or Adult Services should tell people what the alternatives are, for example providing people with a list of what is available, with the distances to them provided.

*“Why don’t you tell us what’s available? Does this mean we’d have to find it ourselves? We need to know about geographical distances.”*

- 11 people specified that they wanted more hands-on help, with an Adult Services team or an individual to help them.

*“It would be helpful to see someone for advice.”*

*“I would need the help from social services to help me organise the right respite for myself.”*

Suggestions included:

- A designated/named care manager or social worker to explore alternatives, coordinate visits to respite places, etc. (three people).
- A person who knows the facilities available and understands the needs of the service user so can organise the right respite to meet

needs, e.g. not put a person with brain injury with people who have learning disabilities (two people).

- A coordinating office at Adult Services to provide details of the options available (one person).
- Brokerage for support to find and book respite (one person).
- Consultation with an Occupational Therapist with regards to the alternatives.

One person said they already had a member of staff helping them.

- Four people said they would like to have the chance to visit suitable alternatives to become familiar with them. Two of the four said it would help to be able to stay at the alternative facilities in advance of a period of respite to get used to them, or try them out to see if they meet needs.

*“Possibly a short stay to ensure that my family, myself and the facility concerned all agree that the facility is suitable and able to provide for my current needs and ongoing developments.”*

- Four said they would like the Council to pay in full for short stays with Vitalise Netley Waterside House or similar accessible holidays.

*“I would want to go to Netley Waterside fully paid for by Social Services but I know this won’t happen due to the cost.”*

*“I would really like to go to Waterside Netley.”*

- Three said they would like John Darling Mall to stay open. They expressed concern that the service user would refuse to go anywhere else or no alternative would meet their needs.

*“Don’t close John Darling Mall. No support or assistance would help my husband to go anywhere else.”*

*“We would rather it does not close. Staff are like family and they know my needs.”*

- Two said they wanted Adult Services to provide updates or keep people informed about availability of respite so they did not miss out.
- One said they wanted reassurance that there will be somewhere suitable to meet his/her particular communication needs and that the staff will take the time to try to understand him/her so they are not left isolated. Another said they would like the Council to pay for respite in private care homes.

*“We have seen care private homes close and now council homes close. Remaining private homes want over a £1000 per week for care. Will the Council fund that?”*

- Two people said they did not know what help they wanted and two queried what help would be on offer to find an alternative. One person said the

question is irrelevant as the Council has a duty of care (i.e. the Council will have to give the help people need).

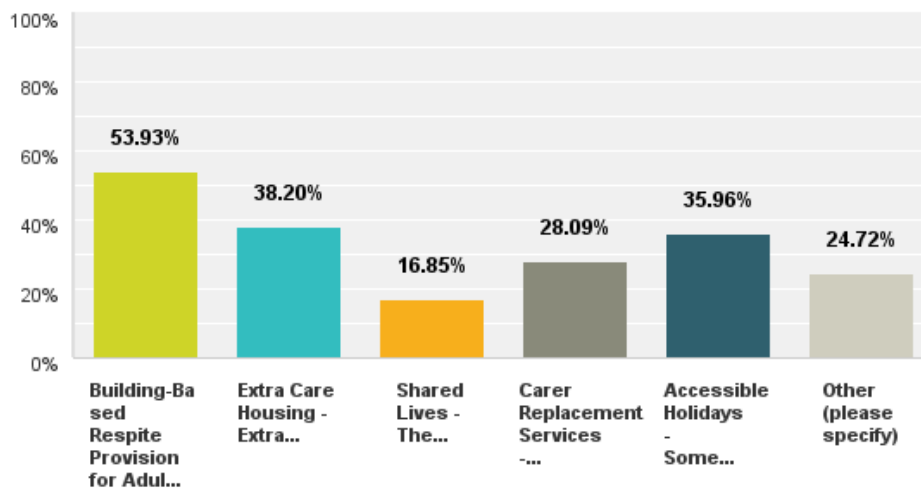
## Section 2: Future respite options for people with a physical disability in Hampshire

### Question 5.

In your opinion, which alternative respite services should the Council be able to offer to people who currently access respite at John Darling Mall? (Please tick all that apply)

**Q5 In your opinion, which alternative respite services should the Council be able to offer to people who currently access respite at John Darling Mall? (Please tick all that apply)**

Answered: 89 Skipped: 13



89 people responded to this question.

- The most frequent choice was for building-based respite provision for adults, with 54% (48 people) ticking this option.
- Extra Care housing was the second most popular choice, chosen by 38% (34 people).
- Accessible holidays were chosen by 36% (32 people).
- 28% of respondents (25 people) chose Carer Replacement Services.
- 17% (15 people) chose Shared Lives.

- 25% of respondents (22 people) chose 'Other'.
  - Asked to explain what 'other' might be, eight respondents said that John Darling Mall should be retained, no option would be better than John Darling Mall, or that no option other than John Darling Mall would be suitable to meet their/people's needs. One said there was a lack of provision for people with physical disabilities.

*"It is/was very hard to find somewhere like John Darling Mall. I would not be happy going anywhere else. It has all that I need and I have made friends here. All of the above options would not suit my needs one way or another."*

*"From the options above none of them offer the same level of access to independent or supported living that you get at John Darling Mall. The residents have level access to all the local shops, services and are able to make full use of them with the staff from John Darling Mall. A nursing home is not the right place to put a person that is trying to be independent. It is not an environment that will help and support you."*

- One respondent said the Council should offer somewhere exactly like John Darling Mall. Another said John Darling Mall should be moved to a smaller building, explaining that the building is the problem – tired and not homely – and not the service.
- One respondent said they preferred commissioned services – it is possible that they meant 'in-house' buildings based services or similar services commissioned from external providers. An external service provider who responded said that the Council could commission them to provide respite in their building-based service for younger adults with physical and /or learning disabilities.
- Two people highlighted the importance of continuity in service. They said that users need to be able to get the same chosen service away from home throughout the year for planned respite, not just staying on an ad hoc basis at whatever service is available at the time. One of them stressed the importance of having familiarity and not having to get used to a new place and explain needs to new people every time. Another person stressed that any buildings-based respite needs to be within a reasonable distance to service users' homes.
- One respondent said the Council should provide Direct Payments so people can buy the respite they need.
- One person said that all of the options listed needed to be available. Another said that alternatives to John Darling Mall need to be friendly, and cater for the level of need, circumstances and independence of people.

- Some people criticised the options listed: one said Shared Lives is not suitable for people in a wheelchair; one said respite in learning disability settings is not suitable for people with physical disabilities.

*“None of these would be appropriate for my husband and he couldn’t tolerate spending time in a learning disability sector.”*

- Two said accessible holidays are only a viable option if they are fully funded by the Council – one said a holiday at Vitalise was the ideal respite for him or her, but it was refused because of cost. One said Extra Care might be an option but people could get isolated or depressed in Extra Care as it would not offer social interaction with their peers. They suggested that respite in Extra Care should be offered as routine for people who wish to move into their own flat.
- One person said they felt there should have been a similar question posed on future accommodation options for the tenants living in the flats.

### **Question 6.**

**Are there any alternative options that you think the Council should consider in relation to the proposed closure of service at John Darling Mall?**

57 people responded to this question.

- The most common option that people suggested was to keep John Darling Mall (19 people). People stressed that it was still needed to give people a break and serve a local need.

*“John Darling Mall is ‘tired and out of date’ but it is comfortable and most people enjoy the care and relaxed atmosphere.”*

*“Shouldn’t close it down as it cuts people’s lives off. It prepared me for living on my own. It’s done a job for me.”*

*“Don’t close it - it is badly needed by people of my husband’s age [58]. If no other suitable respite is provided, then the Council will be paying to house my husband permanently in care which will cost far more than refurbishing John Darling Mall!”*

- 18 people said the Council should replace John Darling Mall with another buildings-based respite centre on site or elsewhere. Suggestions included: move John Darling Mall to a smaller building; knock it down and replace it with a smaller building; build and run a new purpose-built buildings-based respite centre for people with physical disabilities only; or ‘expand the model of John Darling Mall’. Reasons given included ensuring people are not inappropriately mixed with people who have mental impairments, ensuring people do not have to go too far for respite, giving people

continuity of care with staff they know, ensuring people have the opportunity to socialise and maintain friendships, ensuring the need for unplanned and short-notice respite is met, and ensuring people with complex needs or high dependency still have suitable provision. It was suggested that knocking down the John Darling Mall building and replacing it with modern building-based respite would be cheaper than refurbishing the service or building flats. One suggested moving John Darling Mall to a cheaper plot.

*“As John Darling Mall is not being used to its full capacity, could a smaller unit not be built in its place/ Possible a unit purpose built for respite care only, and not as a shared living facility.”*

*“Sell off the site and build a smaller purpose-built facility.”*

*“Build a smaller service with the requirements needed with a smaller staff team so that the current users can still have the support with people they trust and also still be able to maintain friendships with other service users that they would not otherwise see.”*

*“Knock John Darling Mall down and rebuild – it will be more cost-effective! Our lives will be made much more difficult without John Darling Mall. We need local, appropriate respite services.”*

*“If John Darling Mall closes would like another unit established that will primarily cater for people with physical disabilities instead of having to go with mentally handicapped.”*

*“John Darling Mall offers not only care etc. but includes a very important need for clients to be able to socialise like at meal times and communal areas. I feel this is essential to be included in any future developments...living individually may be alright for some but not all... there is a need for those who need help with every aspect of their lives.”*

*“Use some of the money raised by sale of the plot for building, to site a new similar facility at a lower cost site.”*

- 13 people said the Council should refurbish, improve or invest in John Darling Mall. It was thought that refurbishing would stop it being underused and would attract younger disabled people. People believed the service was still needed. Individuals said it was needed by severely disabled people and should stay in place so that people do not have to travel long distances for respite. One said it should be converted into two or three smaller units, for example a high dependency unit, a low dependency unit and one for acquired brain injury or stroke sufferers. Three said the existing spaces, such as the games room, bar and flats, should be used better and suggested they could generate income and help make the service viable. A few people were doubtful that the costs of refurbishment would exceed the costs of other options. One said there needs to be a fully documented financial assessment of the future options,

comparing the cost of updating John Darling Mall with the cost of creating respite care options with learning disability services and the cost of developing Extra Care on the site. One person said the Council should use its reserves to refurbish John Darling Mall.

*“Cannot believe that it would cost £5m to refurbish. If proposed flats are to be built on site anyway would rather see John Darling Mall refurbished probably costing less.”*

*“Spend the money on refurbishment, this consultation will cost money and I am sure like everything else the alternatives will cost money. Think outside the box. If capacity is not 100% think of ways to make it so. Look at leasing or charging other organisations for the rooms. Look at sensible ways of maximising income.”*

A few people, who were not necessarily advocating investing in John Darling Mall, were critical of the service. Two people (one in favour of the proposal and one against) said the bedrooms need to be en suite as it is too difficult to get to the toilets at night. One person (who was not sure if they were for or against the proposal) wanted to see improvements in the staffing as well as the building.

*“John Darling Mall needs to look better and have better staff and improve the way they talk to people. It was very daunting to be spoken to like I was a child.”*

- Three people said that John Darling Mall should be turned into housing. Two of the three said that new flats should be built for disabled people with support services or a warden on site. One said the respite areas should be converted into more sheltered housing flats with a good communal area. One of the three suggested putting a plaque to say that ‘John Darling Mall was here’ if the flats are built.
- Two people said the Council should consider closing an alternative service or should save money elsewhere. Three said the proposed closure was an example of using disabled people as easy targets.

*“We all remember the utterly disastrous care in the community where buildings and services were closed down and patients were left to fend for themselves utterly abandoned by uncaring authority. This sounds the same as the proposals for John Darling Mall.”*

- One person said that people should be offered Direct Payments so they can purchase respite (it should be noted that currently people can buy any respite service with a Direct Payment except in-house services). Another suggested that Personal Assistant-based support could be offered so that family carers can go and have a break whilst the disabled service user remains in their own home (it should be noted that this is already an option available to people).
- One person suggested that Orchard Close (a home currently primarily for people with learning disabilities) could be used for respite.

- A service provider suggested the Council could commission buildings-based respite services and replacement carers with themselves or other external providers.
- Three people expressed concern that the alternative options may not meet people's needs or would be unsuitable.

*"The first time I went I found it very distressing, But the more I went I got used to the surroundings and the staff. I would then look forward to my visit. I would be very worried for people if an alternative place did not offer an environment that they were comfortable with."*

Another said that alternative options need to provide the same feeling of individuality as John Darling Mall creates. One person said there needs to be a range of alternatives, and suggested the Council look at what is available for people seeking respite in those areas of Hampshire where the service users who do not use John Darling Mall live.

- One person said the Council should have maintained the building so it should not need work doing.
- One said that if John Darling Mall is closed, workers should have their employment guaranteed and residents should have 'full care' guaranteed.

## **Question 7.**

### **Do you have any other comments, suggestions or feedback?**

46 people responded to this question.

### **Comments against the proposal**

The majority of comments were against the proposed closure.

- The most common comments were around the theme that it would be a shame to close John Darling Mall as service users and carers do not want it to close; people thought the Council should give more consideration to the negative impact closure of the service may have on people (21 people). 12 people said they, or service users, tenants or carers would be upset or disappointed if it closed and there was some concern that the prospect of closure was causing anxiety and may affect people's mental or physical health. Two people said they or the person they care for needs continuity and did not want to have to go through getting used to new people and a new place again. Two said they or the person they care for would not want to go anywhere else.

*"Think long and hard about this closure. Give some thought about the people who still go there because they love it."*

*"I cannot speak more highly for what John Darling Mall done for myself and my family. I would be very upset and worried for the future respite care of other families if it was to close."*

*“Since hearing the news of the proposed closure... I have had many distressed service users, Stonewater tenants and relatives on the phone, and in person, very anxious and upset. John Darling Mall is more than just a respite service. We may not be able to offer everything we would like but we are a tight community.... It is heart breaking to see our service users and relatives, who I have grown so fond of and close to, be so upset and stressed trying to think where they can go now for their respect, who will understand their needs and be familiar with their personal care routines and preferences.”*

*“What Hampshire County Council don’t understand is the burden placed on families with no respite.”*

*“I feel very unsettled since this started and my anxiety has gone through the roof.”*

- 11 people commented that they were against the proposal because of the quality of the service or facilities there – some said that they felt no other service would be better than John Darling Mall. Specific features people praised included
  - Excellent or good staff (four people).
  - High quality of care- people are looked after (three people).
  - Staff who know the service user and understand their needs (two people).
  - Excellent or good food (two people).
  - Giving people independence (two people).
  - Keeping people safe (one person).
  - Purpose built (one person).
  - Mall (one person).
  - Level access to chemist, café’s shopping etc. (one person)

*“I love it and don’t want to go anywhere else. I can be on my own and do what I want to there; staff are there if I need them.”*

*“A number of my previous clients have benefitted from the independent living flats and have indeed moved on to their own accommodation successfully. Without this facility their chances of a successful transition would have been significantly diminished.”*

*“It’s like Kew gardens but my brother called it a glorified garage. I like it as it is all covered and you didn’t get wet.”*

One person who was neither for nor against the proposal said that it was a shame to break up a good team by closing John Darling Mall, and expressed the view that the staff are more important than the look of the building. Another who was neither for nor against the proposal said the service is very outdated.

- Eight people made comments objecting to the proposal on the theme that the alternative options for respite are unsuitable for service users. Four of the eight said it is inappropriate to put people with physical disabilities in services designed for people with learning disabilities, three said an older people's home is not suitable for people with physical disabilities who are not old, and three said it would be inappropriate to put physically disabled people in a service with people who have Alzheimer's or dementia as they need mental stimulation. Two people stressed the need for people to be able to socialise with their peers in respite.

*"My husband did not choose to have a physical disability, nor did those who access the John Darling Mall service. All the options you have given following the closure of John Darling Mall are only learning disability environments."*

*"A service user told me that he definitely did not want to go into a learning disability service as he wanted to be with people "I can talk to about current affairs and the news." He had previously had a bad experience in a private nursing home where other residents had dementia. His family carer said there is nothing wrong with his mind it's just his body so he needs to be with people like him."*

*"Social aspect is vital for respite options with people you have things in common with."*

One said the other plausible options for respite are too far away for them. Another said buildings-based respite is needed for those who have to have adapted buildings, e.g. people in wheelchairs. One person said carer replacement services are not an alternative to respite at John Darling Mall as the carer would have to leave the home to get a break and queried where they would go.

- Five people commented against the proposal on the basis that there is little other provision for people with physical disabilities and it is the Council's only respite centre for people with physical disabilities. One of them stressed that any alternatives would need the right level of staffing for someone with high dependency – 24/7 staffing with nursing skills.

*"I do wish there was more facilities in the New Forest and Waterside area for people with just severe physical disabilities."*

- Five people said John Darling Mall should be invested in, upgraded or rebuilt. There was a view that making it more modern would appeal to younger disabled people. One of the five said the service should be relocated so standards can be met and a better service provided. Two said the food needs improving. One said there needs to be en-suite rooms. One said there needs to be provision of exercise – when they attended there was a gym but no one available to supervise physiotherapy in it.

*“HCC should spend monies to rebuild John Darling Mall so that it can be used for its original intention of respite for all ages thereby saving taxpayers in the long term.”*

- Three people made comments on the theme that John Darling Mall has the potential to be well used but has been deliberately run down or neglected. One of them thought that income could have been generated if the facilities were used more creatively.
- Two people said they were against the proposal as, in their view, keeping the service open would save taxpayers money in the long run.

*“John Darling Mall has been a vital service in the area for many years and you should look at the benefits this has made to those people’s lives and how much less money you are paying for them in care and housing costs.”*

- Two Stonewater Housing tenants commented that they were against the proposal as they did not want to leave their home. One person said more should have been done with the tenants to discuss the proposed closure with them and reassure them.

*“If I was a taxpayer only looking at the money it would cost to improve the building I would say close John Darling Mall. However, I’m not. It’s my home. John Darling Mall respite seems to be for older people, younger people don’t want to come here. The building is not fit for purpose... Over the 10 years the building has been neglected. This consultation doesn’t shock me. It’s not viable to keep open a unit that isn’t used... Having said all this I don’t agree with the closure as I live here and would have to move and it’s not my choice to move.”*

*“I would have to move out if John Darling Mall closed. I am worried about it.”*

- Four people said that closing John Darling Mall would be discriminating against people with physical disabilities or harming the most vulnerable. People were unhappy with the closure of services for disabled people.

*“Don’t close John Darling Mall – you will harm the most vulnerable and to the additional detriment of their families and the wider community.”*

*“You seem to be discriminating towards those with physical disabilities and only providing services for those with learning disabilities.”*

*“Vanguard Centre in Cosham was purpose built for use by disabled people. It was an ideal place for my husband to have a break one day a week. However it was closed. It seems a shame to see John Darling Mall go the same way.”*

### Comments in favour of the proposal

- Three people who said they were in favour of the proposal commented on experiencing a depressing atmosphere there or treatment from staff that did not support independence, choice and control.

*"I've used John Darling Mall for 14 years and it has got really bad"*

*"You come into a building like this and you feel utterly down."*

*"Disabled people should train the staff. Staff should spend time in a wheelchair - at least 1 or 2 weeks in a wheelchair so they can see it from our point of view and our eye level."*

- Two people said that they were in favour of the proposal as it would be expensive to improve the building and it was not worth the money for the number of people who use it.
- One said John Darling Mall should be knocked down and new flats with support services built in its place.

### Other comments

- Four people said they thought the consultation was a sham and that the Council had already decided to close John Darling Mall.

*"When I attended my consultation interview the person conducting the consultation gave me the impression that the decision had already been made and that this consultation was only being done to make it look like the public had been given a chance to have their say about the future of John Darling Mall."*

- Two people said not enough information or evidence had been provided in the consultation period on resources, demand and the Council's priorities to enable people to draw their own conclusions.
- One person (who was in favour of the proposal) said that John Darling Mall was good for people that came for rehabilitation and that the Council should look into providing that sort of service again.
- One person queried how respite would fit with Direct Payments as Direct Payments may become the default in the future.
- One person said the real issue with John Darling Mall is not lack of potential clients but the cost of stays.
- One person said the Council is being driven by the need to cater for the younger generation who do not like to go to John Darling Mall.
- One said they wrote a letter to several staff at John Darling Mall and did not receive a reply – they said they hoped that the staff received the letter.
- Commenting on things they would like to see at respite in the future, one person said they would like to have someone to talk to at respite who is

not their own family, e.g. a counsellor and another said the Council should get staff who speak English.

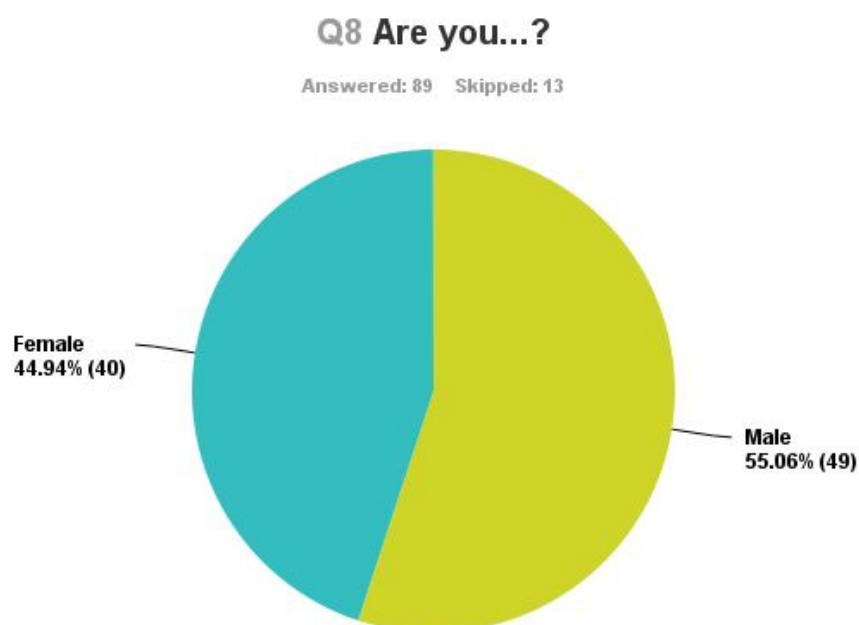
## Section 3: About you

### Question 8.

#### Are you...?

89 people answered this question.

- 55% (49 people) were male
- 45% (40 people) were female



### Question 9.

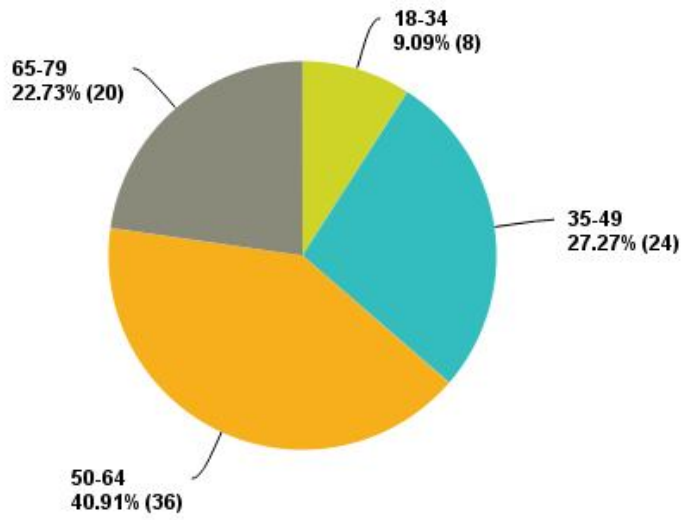
#### Please indicate your age range.

88 people answered this question.

- The biggest age group was 50-64, with 41% of respondents (36 people) in this group.
- All respondents were under 80.
- 9% of respondents (8 people) were aged between 18 and 34.
- 27% (24 people) were aged 35-49.
- 23% (20 people) were between 65 and 79 years old.

### Q9 Please indicate your age range.

Answered: 88 Skipped: 14

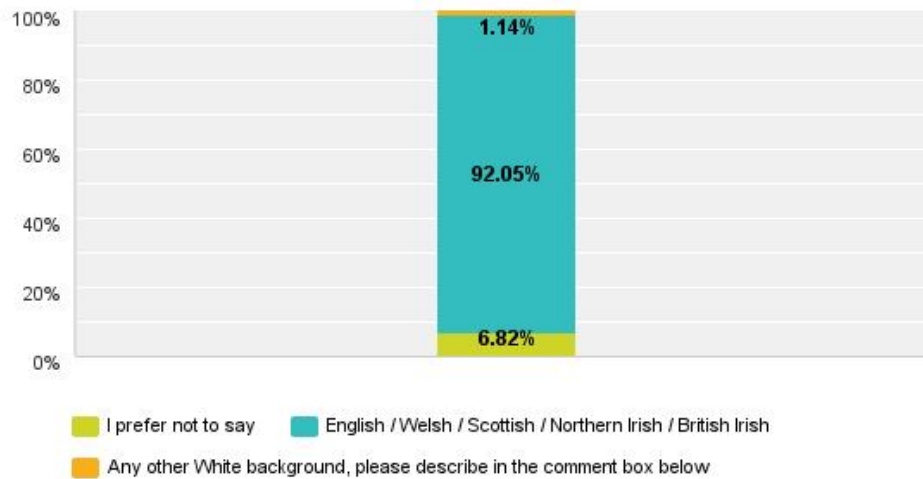


## Question 10.

### What is your ethnic group?

#### Q10 What is your ethnic group? Please tick one option that best describes your ethnic group or background

Answered: 88 Skipped: 14



88 people answered this question.

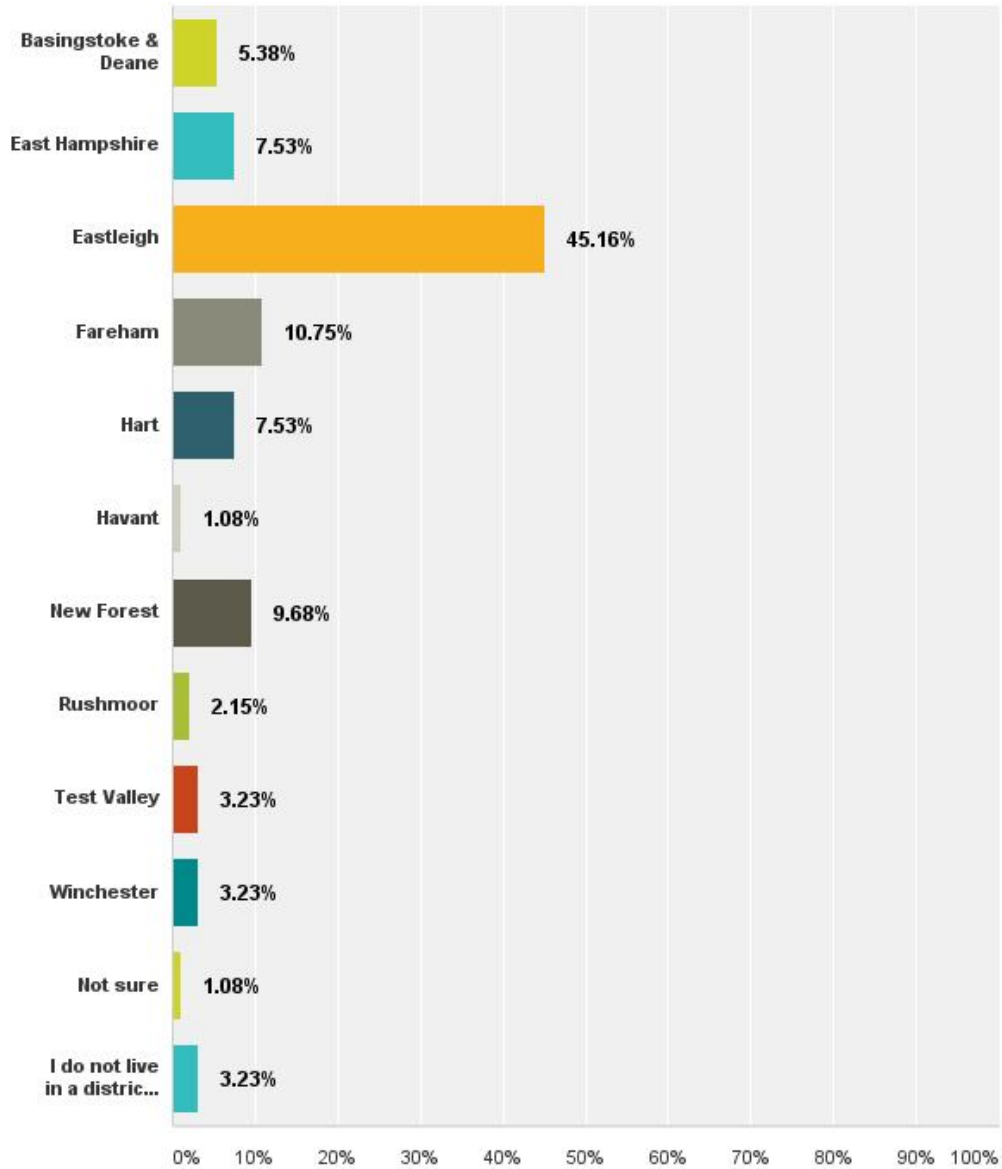
- 92% (81 people) described themselves as White: English / Welsh / Scottish / Northern Irish / British.
- Almost 7% (6 people) preferred not to state their ethnicity.
- One person described themselves as English/French.
- In the box for comments, an organisation explained that they included all ethnicities.

**Question 11.**

**Please tick one box to indicate with district of Hampshire you live in.**

**Q11 Please tick one box to indicate which district of Hampshire you live in.**

Answered: 93 Skipped: 9



250 answered this question.

- The majority of respondents (45%, 42 people) were from Eastleigh.
- 11% (10 people) were from Fareham, 10% (9 people) were from the New Forest, 8% (7 people) were from East Hampshire and another 8% (7 people) were from Hart.
- 5% (5 people) were from Basingstoke and Deane.
- There was at least one respondent from every district except Gosport.

### ***What people told us: letters and emails***

One letter and one email were received from people who also completed questionnaires. Both the letter and email were in objection to the proposal and both criticised the proposed alternative services. Key points included:

- People with physical disabilities mix poorly with people with learning disabilities.
- Young physically disabled people will gain no benefit or respite from staying in an old people's home.
- The use of existing units for learning disabilities and older people will lead to an inappropriate mix and mean people with physical disabilities will use accommodation that is not adequately designed for them. John Darling Mall offers appropriate care and accommodation.
- Accessible holidays are not affordable as the Council will not fully fund them, thus not a viable alternative.
- Extra Care, Shared Lives and Carer Replacement Services will not offer the opportunity to network with peers. They mean spending time with strangers with whom the service user may not be compatible, and may not have the right equipment needed or provide a satisfactory level of care.

The letter also included the following points:

- John Darling Mall provides a network of supportive staff and friends who have become a big part of service users' lives.
- Not knowing where to go for respite means service users cannot plan for future events.
- The Council should think about the emotional impact that the consultation is having and proposed closure will have on service users, relatives and the staff who may not see one another again as a result.

The letter also expressed the view that the Council does not care about service users. It expressed the view that the decision to close has already been made and that the consultation is just for show.

## ***Conclusion***

Whilst there was a small amount of support for the proposal, the majority of consultation responses were against the proposal, with people mainly objecting because they valued John Darling Mall and thought that it should be retained in some form, or they considered that the alternatives proposed would not be suitable to meet people's needs.

Appendix A: Questionnaire

# Respite care for people with physical disabilities in Hampshire

Public Consultation

13<sup>th</sup> July – 4<sup>th</sup> September 2015

This information, the questionnaire and report can be requested in alternative formats such as large print and Braille by e-mailing:

E-mail:

[adultservices.communications@hants.gov.uk](mailto:adultservices.communications@hants.gov.uk)

or by calling:

Tel: 0300 555 1386



Hampshire  
County Council

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## **Introduction and background**

We are proposing to close the respite service at John Darling Mall in Eastleigh and would like your views on this proposal.

### **Why are we making this proposal?**

The way social care is provided is changing in England, particularly in the light of the Care Act 2014, which places an emphasis on wellbeing, prevention and early intervention and individual choice. People want more choice and control over their care and new services need to be developed to meet their individual needs.

In addition to this, we are also now seeing a steady rise in the number of people with complex care needs who require our support. This is driven by a number of factors including the increasing success of health interventions that are helping people to live longer, but not always in good health. Many younger people with profound disabilities are also now surviving into adulthood. While this is to be celebrated, many need significant long term support.

With this growing number of people with complex, long term care needs, the requirement for modern and adaptable respite accommodation is growing, as are the numbers of people looking for alternative ways of receiving respite support.

The County Council is continuing to review the support services provided in the community and recognises the importance of good quality respite provision both for those needing care, and for those who care for them. Decisions on individual services are taken within this context, as well as that of the significant financial challenges the County Council is facing and the on-going need to find savings and ensure good value for money for the Hampshire taxpayer.

## **Further information**

**We would like your views on our proposal to close the respite service at John Darling Mall (JDM) and have set out some additional information in the following pages to help you respond. This covers:**

- **The JDM building**
- **How the respite service at JDM is used**
- **The alternative respite services available**
- **Future use of the site**

### **The JDM Building**

John Darling Mall in Eastleigh was built by Hampshire County Council in 1985 as a purpose built 24-bed rehabilitation unit also providing respite care for people aged between 18 and 65 with physical disabilities. Over time its focus has moved to offering respite services for adults with physical disabilities.

The building is in need of considerable investment, including mechanical and electrical works and the replacement of the heating system, to maintain it for its current use. The building is poorly insulated with partly-outdoor communal spaces which tend to be damp and cold in winter.

More importantly, the physical environment is not suitable for people with profound and multiple disabilities and others requiring intensive support.

The room sizes are not as large as expected in modern services and the walls and ceilings are not strong enough to support the hoists needed in a modern service. .

There are not enough personal care areas and bathing and showering facilities to provide a modern standard of care. Any refurbishment of John Darling Mall would require significant

restructure of the interior of the building. The current estimate is that bringing it up to modern standards would cost around £5m.

### **Current Use of John Darling Mall**

The building is purpose built for up to 24 people. Six of the accommodation units within the building are leased to Stonewater Housing Association (formerly Raglan Housing Association), five of which are currently occupied. Of the remaining 18, a maximum of 12 are currently in use. The average occupancy is between five (42%) and seven (58%) units per night.

During 2014/15, 65 people who are Hampshire residents and two people from outside the county used John Darling Mall. The people who used John Darling Mall came from all over Hampshire, with the largest number coming from Eastleigh, Fareham, Hart and the New Forest.

The age range of people using JDM is 19-79 years old. During 2014/15, 80% of the people who accessed the service were aged over 50. Only 13% of the people who used the service were under 40.

Overall, we are seeing the number of people using JDM decreasing, particularly among younger people who are tending now to choose alternative respite options.

### **Staffing**

John Darling Mall has a manager, deputy manager and 26 other members of staff. Should the decision, following consultation, be to close the John Darling Mall service, we would offer the staff other roles working for Hampshire County Council. No redundancies are proposed. The staff would be offered any additional training they may need for future, alternative roles.

### **Other Respite Services Available**

Hampshire County Council offers a number of respite options for Hampshire residents, dependent upon an individual's wishes or requirements:

### *Building-Based Respite Provision for Adults*

Hampshire County Council would be able offer building-based respite services at a number of its other facilities across Hampshire, including residential and nursing homes such as Oakridge residential and nursing home in Basingstoke, for those individuals who wanted to go there.

Croft House in Fareham is currently run by Hampshire County Council as a residential care home offering respite care and crisis care for people with learning disabilities. Re-configuring its current usage (currently only six beds / rooms are in use) would allow it to also be used to offer respite for people who might currently use John Darling Mall. Should a decision be taken to close John Darling Mall, then the Council will explore this option to provide respite services for people with physical disabilities, including potential dedicated sessions for people with physical disabilities.

Hindson House is a 6-bed respite unit for people with learning disabilities located in Basingstoke that is owned and run by Hampshire County Council. All rooms and facilities are fully accessible for people with physical disabilities; in the event that John Darling Mall should close then the Council will explore the use of this facility to also provide respite services for people with physical disabilities, including potential dedicated sessions for people with physical disabilities.

Other Hampshire County Council facilities that would also be considered include Orchard Close a 15-bed respite unit for people with learning disabilities located on Hayling Island. The option of potentially using Jacob's Lodge, a residential home for people with learning disabilities in Totton would also be considered.

### *Extra Care Housing*

Based on the outcomes of the meetings with individual service users, in the event that a decision is made to close John Darling Mall, the Council would look at leasing an adequate number of flats in existing Extra Care Housing schemes on a long-term basis that could be used for respite. Potential sites have been identified, and the Council would work to ensure there would be an appropriate geographical distribution of flats to meet the requirements of those people who may wish to use such facilities.

### *Shared Lives*

Hampshire County Council is currently looking to review and expand its Shared Lives service. The Shared Lives scheme is a service provided by individuals and families in their own home across Hampshire who want to offer a vulnerable person respite, day care or long term care. Within the proposals is the requirement to recruit more specialist Shared Lives carers, including for people with physical disabilities, who could offer respite. Should the decision be made to close John Darling Mall, then the Shared Lives scheme would pro-actively recruit carers who could offer respite for people with physical disabilities.

### *Carer Replacement Services*

There are a number of organisations that offer a carer replacement service, offering respite for both carer and service user. This involves provision of respite in the home of the service user, allowing the carer to take a break, whilst the service user stays at home. The market consists of national organisations such as Interserve Healthcare ([www.interservecareathome.com](http://www.interservecareathome.com)) as well as local providers such as Logacare ([www.logacare.com](http://www.logacare.com)), based in Farnham.

A number of these organisations also offer services with a carer accompanying the service user and usual carer on holidays, managing their clinical and care needs, allowing the whole family to holiday together.

## *Accessible Holidays*

There are a number of organisations that provide holidays for people with physical disabilities. These holidays tend to fall into 2 categories; those that offer accessible accommodation for people with disabilities and those that offer care / support to the service user as part of the package. In the case of the former, in order to provide respite to the usual carer, it may be necessary to purchase additional care to accompany them on holiday.

Netley Waterside House (Netley, Southampton), run by Vitalise ([www.vitalise.org.uk](http://www.vitalise.org.uk)) offers respite and breaks for adults with physical disabilities, older people and carers. The breaks include a wide range of activities and excursions with 24-hour nursing care on-call and personal support.

Holidays for All ([www.holidaysforall.org](http://www.holidaysforall.org)) acts as an umbrella organisation covering a number of UK charities and specialist tour companies that offer holidays, both in the UK and abroad, to people with disabilities. For younger adults (18-25), Phab ([www.phab.org.uk](http://www.phab.org.uk)) offers a variety of holidays and residential projects.

There are also a number of commercial disabled holidays travel agents, offering the same services as mainstream travel agents, however specialising in holidays for people with disabilities. One such agency is Disabled Holiday Directory ([www.disabledholidaydirectory.co.uk](http://www.disabledholidaydirectory.co.uk)) which works in partnership with mainstream tour operators.

## **Future Use of Site**

Although John Darling Mall is owned by Hampshire County Council, Stonewater Housing Association leases six independent living flats that are an integral part of the John Darling Mall complex. Given this agreement by both parties is needed around the future of the site.

Should the decision be made to close John Darling Mall, Hampshire County Council would propose to develop Extra Care Housing for adults with disabilities on the current site.

Hampshire County Council's long term strategic approach is to enable the development of a wider range of services to meet the housing care and support needs of adults with disabilities with an eligible social care need that maximise independence and minimise cost to the taxpayer. This model of housing offers high quality accommodation and support for adults who primarily have a learning disability, mental health problems or a physical disability.

Extra-Care Housing for adults with disabilities is part of a range of offerings to meet the housing and care needs of younger adults, and sits alongside other supported living models. It particularly provides an alternative to residential care and offers greater independence and choice for people.

## Consultation

This County Council is seeking views on the proposed closure of the physical disability respite service at John Darling Mall in Eastleigh.

The questionnaire is divided into three sections:

- **Section 1** – The proposed service closure
- **Section 2** – Future respite options for people with a physical disability in Hampshire
- **Section 3** – About You

Responding to the consultation is entirely voluntary. If you would like to respond, you will find further useful information on the dedicated webpage:

[www.hants.gov.uk/johndarlingmall-consultation](http://www.hants.gov.uk/johndarlingmall-consultation)

Alternatively you can request a printed copy of the report by e-mailing:

E-mail: [adultservices.communications@hants.gov.uk](mailto:adultservices.communications@hants.gov.uk)

or by calling:

Tel: 0300 555 1386.

Please omit any questions you feel are irrelevant to you. The questionnaire takes approximately 15 minutes to complete.

All responses to the consultation will be treated as confidential. This means that when the results are reported we may quote what you have told us but you will not be identifiable. The responses will be kept securely for one year and then destroyed.

The consultation results, and analysis of the findings, will be published and presented to the Executive Member for Adult Social Care, Cllr Liz Fairhurst, on 25 November 2015, along with a final recommendation on the future of the service at John Darling Mall.

Please post your completed questionnaire, to reach us by **4 September 2015**, by using the pre-paid envelope provided (you do not need to use a stamp).

# Section 1

## The proposed service closure

The County Council is proposing to close the physical disability respite service offered at John Darling Mall in Eastleigh.

### 1. How would you describe your attitude to this proposal?

*Please tick one box*

- Strongly in favour.....
- In favour.....
- Neither in favour nor against.....
- Against.....
- Strongly against.....
- Not sure.....

If you would like to give the reasons for your answer choice, please do so below.

***Questions continue on the next page.....***

**2. Do you have a connection with John Darling Mall?**

- Yes.....
- No.....

**3. Which of the following best describes your connection?**

- I use John Darling Mall for respite.....
- I am a family member/carer of somebody that uses John Darling Mall for respite.....
- I am a member of the local community.....
- I am a member of a local voluntary/community group.....
- I am a tenant of Stonewater Housing.....
- Other, *please specify in the box below*.....

***Questions continue on the next page.....***

**For respite users and their families only**

***If you are not a respite user or family member/carer, please go to Section 2 (next page)***

- 4. If the Council decides to close the service at John Darling Mall, what support or practical assistance would you like to help you find alternative respite provision?**

*Please write in the box below*

***Questions continue on the next page.....***

## Section 2

### Future respite options for people with a physical disability in Hampshire

We would like to ask you some questions about your views on alternative respite options for people with a physical disability.

**5. In your opinion, which alternative respite services should the Council be able to offer to people who currently access respite at John Darling Mall? (Please tick all that apply)**

***Building-Based Respite Provision for Adults***

Building-based respite services could be offered at a number of the Council's other facilities across Hampshire, including residential and nursing homes.

***Extra Care Housing***

Extra Care housing offers a secure place for somebody to live in an apartment for respite with care and support on hand 24 hours a day, 7 days a week.

***Shared Lives***

The Shared Lives scheme is a service provided by individuals and families in their own home across Hampshire who want to offer a vulnerable person a short break, day care, long term care or respite care.

***Carer Replacement Services***

There are a number of organisations that offer a carer replacement service, offering respite for both carer and service user. This involves provision of respite in the home of the service user, allowing the carer to take a break, whilst the service user stays at home.

***Accessible Holidays***

Some organisations provide holidays for people with physical disabilities. These holidays include those that offer accessible accommodation for people with disabilities; and those that offer care

/ support to the service user as part of the package. In the case of the former, in order to provide respite to the usual carer, it may be necessary to purchase additional care to accompany them on holiday.

***Other (please specify)***

**6. Are there any other alternative options that you think the Council should consider in relation to the proposed closure of service at John Darling Mall?**

**7. Do you have any other comments, suggestions or feedback? *Please write in the box below***

## Section 3

### About you

The information you provide here is voluntary and confidential. You do not have to fill in this section if you do not want to. If you complete this section you will be agreeing to us holding this information but using it for monitoring purposes only. Please tick the boxes that apply to you.

**1 Are you...? Please tick one box**

- Male.....

- Female.....

**2 Please indicate your age range. Please tick one box**

- 18 – 34.....

- 35 – 49.....

- 50 – 64.....

- 65 – 79.....

- 80 or over....

***Questions continue on the next page...***

**3 What is your ethnic group? Please tick one option that best describes your ethnic group or background**

- I prefer not to say.....

**White**

- English / Welsh / Scottish / Northern Irish / British .....

- Irish.....

- Gypsy or Irish Traveller .....

- Any other White background, please describe:.....

**Mixed / Multiple ethnic groups**

- White and Black Caribbean.....

- White and Black African.....

- White and Asian .....

- Any other Mixed / Multiple ethnic background, please describe:.....

**Asian / Asian British**

- Indian .....

- Pakistani .....

- Bangladeshi .....

- Chinese .....

- Any other Asian background, please describe: .....

**Black / African / Caribbean / Black British**

- African .....

- Caribbean .....

- Any other Black / African / Caribbean background, please describe: .....

**Other ethnic group**

- Arab .....

- Any other ethnic group, please describe:.....

**4 Please tick one box to indicate which district of Hampshire you live in.**

- Basingstoke & Deane..
- East Hampshire.....
- Eastleigh.....
- Fareham.....
- Gosport.....
- Hart.....
- Havant.....
- New Forest.....
- Rushmoor.....
- Test Valley.....
- Winchester .....
- Not sure.....
- I do not live in a district of Hampshire.....

Thank you for completing this questionnaire.

Please post your completed questionnaire, to reach us by **4 September 2015**, by using the pre-paid envelope provided (you do not need to use a stamp).