COMMUNITY & ADULT SERVICES SCRUTINY COMMITTEE

20 JANUARY 2016

Present: County Councillor McGarry(Chairperson)

County Councillors Ali Ahmed, Carter, Chris Davis, Lomax and

Sanders

59 : APOLOGIES FOR ABSENCE

There were no apologies for absence received.

60 : DECLARATIONS OF INTEREST

Declarations of interest were received from Councillors Lomax and Sanders.

Councillor Lomax declared a personal interest as he lives in sheltered accommodation provided by Cardiff Council.

Councillor Sanders declared a personal interest as she arranges domiciliary care for a family member.

61 : MINUTES

The minutes of the meeting held on 6 January 2016 were agreed as a correct record and signed by the Chairperson.

62 : BUDGET PROPOSALS FOR CONSULTATION

The Chairperson welcomed Melanie Andrews representing Oldwell Court and Sue Phelps representing the Alzheimer's Society to the meeting and invited them to make their presentation to Committee.

Alzheimer's Society Presentation

I would like to thank Scrutiny for allowing me to address this meeting on behalf of Alzheimer's Society. Sue Phelps, the Director for Alzheimer's Society and I will welcome any questions you may have straight afterwards

As part of this address I will outline the reasons why Alzheimer's Society opposes the current Proposed Day Opportunities Strategy by focusing on the following key areas:

- The scale of dementia in Cardiff
- Cost of the provision
- Impact of Day Support Services for people with dementia
- The flaws with the consultation process

Taking a look at the dementia context

There are almost 4000 people with a diagnosis of dementia living in Cardiff. Our capital city has the highest prevalence of dementia in Wales with this figure set to rise by 53% within the next 14 years.

In addition the population is set to rise particularly of those over the age of 65 by 12 % within the next five years.

The diagnosis rate in Cardiff is at just 48% so it's reasonable to conclude that there are in fact approximately 8000 people affected by dementia living in this city today.

Towards the end of last year, Welsh Government released funding to Health Boards across Wales to improve the diagnosis rate. It is reasonable to anticipate, therefore, an increase in the demand for dementia services as the diagnosis rate increases.

Dementia Services in this city are already stretched. We agree with the council that it is vital that these services are fully planned for and properly resourced to cope with this projected demand on resources. Alzheimer's Society would welcome an opportunity to work collaboratively with the council as a critical friend and specialist resource to plan and develop future programmes of support.

What the council currently funds Alzheimer's Society to deliver:

Cardiff Council currently funds Alzheimer's Society £161,000 per year to operate a city wide, specialist Day Support Service for people with dementia based in Oldwell Court, Penylan.

This funding pays for the block purchasing of 19 places per day and since April this financial year 97 families have benefitted from this vital service.

This is a cost effective service - we currently charge the council £29.28 /around £30 per person per session as part of this block booking. It's important to note that whilst this unit cost isn't sustainable in the longer term, Alzheimer's Society can continue to operate at a lower unit cost than is quoted within the strategy -which is £40 per person per session.

Alzheimer's Society notes statements issued to the press by Cardiff Council, at scrutiny on 4th November and within the consultation questionnaire that our Day Support Service works with lower level dementia need only. I would like to share with you some facts that counteract this view:

An audit of our current service users highlights that 64% of service users fall within the severe end of need and require assistance with such things as personal care, one to one support and or "directing" due to heightened confusion levels.

Here are just some of the comments taken from a range of your own Case Managers' referrals to our Day Support service:

- Service User has Diabetes, is partially blind and has late stage dementia
- Advanced dementia
- Moderate to severe symptoms of dementia
- Service User T has cognitive issues which severely impair him on a day to day basis
- Wife desperate for support
- Service User M requires one to one support whilst in the day centre. Parkinson's disease causes M to shake uncontrollably.
- Personal care is required

Very poor mobility requires supervision when mobilising

And just to illustrate this point further, our Day Support Service received a referral recently from a Cardiff council Social Worker. In this referral the SW states that the client attended a generic day centre [such as the two being proposed in Fairwater and Minehead] and that her behaviour was so challenging that felt it was beyond their capabilities to manage her in a centre setting].

The only stipulation we make is that service users are able to bear their own weight i.e. stand unaided because the current accommodation at Oldwell does not have the space to accommodate the use of hoists. It is important here to note that Oldwell Court is not our Day Support Service - it's merely a building which houses our service. Our service can support those who are not weight bearing -we have the capability and expertise within our

workforce but the current layout of the accommodation provided by the council, does not enable us to provide this.

Consultation - the process and flaws

I would like to take this opportunity to reflect and provide feedback on the Consultation Process itself which Alzheimer's Society view as flawed.

It is my understanding that 1700 individuals were written to and offered an opportunity to attend one of three consultation events and I or to complete and return a survey. The letter sent contained inaccurate times e.g. the meeting on 4th January was to be held at 2 am at the Llanrumney Hub and not 2pm. The letter provided no addresses for the meetings and offered dates which were difficult for many families to attend e.g. 16th December -just a few days before Christmas.

For the 4th January meeting, officers arrived late and had failed to book a room which left many elderly carers having to un stack chairs in order to sit down. When officers arrived, carers and people with dementia attending the meeting were told it would be too late to set up the power point presentation. Carers reported feeling devalued and outraged by this experience.

I would also like to note that the questionnaire itself, contains many typographical errors e.g. closing date of February 2015 but more importantly invites people to respond to a leading and inaccurate statement contained on page 4 of the Questionnaire.

On Friday afternoon Sue Phelps and I met with the Director of Communities, Housing & Customer Care Sarah McGill and the Director of Social Services, Tony Young together with two other senior officers. It is important to note that this meeting was constructive and both Sue and I felt encouraged that senior officers appear to be listening to the concerns of people affected by dementia. We discussed how we would mitigate the negative impact of the strategy should it go ahead and explored an incremental decommissioning option for our Day Support Service which would protect existing places via a spot purchasing route.

However for future service users affected by dementia it's vital that the council reconsiders and revises this strategy.

In conclusion, it will come as no surprise that Alzheimer's Society and the 3,800 people who have signed the petition to save Oldwell Court do not and cannot support this proposed Day Opportunities strategy as it currently stands because we do not believe it serves the current and future needs of people affected by dementia. The strategy has a re-enabling model which sets out a preventative strategy for Day Support Services - this cannot apply to those with dementia because the need for Day Support is sadly inevitable. The two last government reviews into our failing residential care note that without a robust Day Support system, people with dementia are often admitted unnecessarily into hospital, stay two weeks longer than those without dementia and are more likely to go into care sooner. Failure to implement such a robust day support strategy will increase costs as well as having a profoundly negative impact on quality of life for people with dementia and their carers.

Alzheimer's Society recognises and understands the financial pressures the council faces but requests that Scrutiny formally recommends the revision of strategy to safeguard existing and future dementia services - Carers are already enduring high level of financial, emotional and physical strain- to ask any more of them will have a devastating impact on our Welsh economy and society.

In summary

- In it's current form, the proposed Day Opportunities Strategy does not meet the specialised needs of people with dementia
- The proposed strategy is silent as to how the Council will respond to the substantial growth in need which is well researched and inevitable
- The reenabling model proposed within the strategy does not reflect the progressive nature of dementia

Sue Phelps from the Alzheimer's Society added that the whole of Wales would be looking at Cardiff and how it responds; Mark Drakeford AM supported dementia friendly communities that support people living in their communities for as long as possible; Social Care needed to be protected with a quarter of hospital beds in wales being taken by people with Dementia, this was costly and unfair.

It was added that Dementia would get bigger year on year and a long term approach was now needed, with pressure on carers and families becoming greater.

The Chairperson thanked Melanie Andrews and Sue Phelps for their presentation and invited questions and comments from Members:

- Members asked how diagnosis rates were known and were advised that it was based on prevalence.
- Members made reference to the 19 places available at Oldwell Court and asked if the current contract with the Council used all these places. Members were advised that the funding was 19 places, capacity at Oldwell Court was 22 places so 3 places were private places. For the 19 places, 65 individuals used the facility, some once a week, some more often.
- With reference to Equality Impact Assessment, Members noted it stated replacing the facility with Council run day centres to meet the needs; Members sought witnesses thoughts on this. Members were advised that some service

users do use generic day centres as well as Oldwell Court and that staff at the generic day centres find some people with dementia difficult to manage; staff and volunteers at Oldwell Court have received specialist training and knowledge, the service is very specific.

- Members asked if the NHS should be helping more. Members were advised that as dementia is an illness then yes they should help after the diagnosis is made. It was noted that dementia patients are charged for the care they receive and this is discriminatory; there should be a better balance of care and responsibility as two thirds of the cost for care is borne by carers and families.
- With reference to the generic day centres, Members asked what impact this would have on people currently using Oldwell Court. Members were advised that people with dementia need specialist care and that uprooting them to a different place with different staff would be detrimental and carers are deeply concerned by the prospect. It was added that the majority of service users stay at Oldwell Court until the very end and are there a long time, staff work holistically with the whole family. Witnesses were concerned that staff at generic day centres would not be able to cope with such complex needs.

Witnesses added that it was frustrating there was a view that Oldwell Court worked with low levels of need when people stayed there to severe stages of dementia. Sue Phelps added that, having met with Tony Young and Sarah McGill, she was encouraged existing service users would not be moved; however the Alzheimer's Society were concerned for future service users as well.

The Chairperson thanked Melanie Andrews and Sue Phelps for their contribution and for answering Members questions.

The Chairperson welcomed Dr David Suthers to Committee and invited him to make his presentation.

Dr David Suthers Presentation

My wife was diagnosed with Alzheimer's about 5 years ago. Looking back it was the beginning of a long hard journey. From the start the Alzheimer's Society has given me great support as a carer, on a permanent basis. The other agencies including Doctors and most ward nurses know very little about Alzheimer's.

I understand that the council is withdrawing funding from Oldwell Court Day Centre by a total of £161,500 which not only puts the service under threat but puts some 14 paid staff under threat. Could Cardiff Council provide 14 care staff for £161,500?

This Day Centre provides care for folk who have slight and moderate levels of Alzheimer's as well as those who are approaching severe levels.

If Oldwell Court has to close where will those who have slight/moderate levels go for care? Will they be left at home, many on their own, to face worsening levels of Dementia, with increased burden on carers, neighbours, and your social services.

What is Cardiff Council going to do to support those carers?

How will Cardiff Council deal with the 4000 Cardiff people already diagnosed and rising by 53% within the next 14 years?

People suffering with Cancer have Macmillan nurses, people suffering with Alzheimer's/Dementia only have the Alzheimer's Society.

The Chairperson thanked Dr David Suthers for his presentation and invited questions and comments from Members:

- Members asked what changes would need to be made to generic day centres
 to make them more a more viable and suitable option for people with
 dementia. Dr Suthers stated that they would need to appreciate the needs of
 the service user more than they currently do.
- Members were advised that the Alzheimer's Society provide advice and information services and lobby on carers behalf, they don't solely provide care.

The Chairperson thanked Dr Suthers for his contributions and for answering Members questions.

The Chairperson welcomed Karen Deehan and Meryl Randell-Jones to the meeting and invited them to make their presentation to Committee:

Jane Jones Presentation - Karen Deehan/Meryl Randell-Jones

Mum is 86 years old and lives independently in Whitchurch with support from Cardiff Council funded domiciliary care and of course us and our families.

She was widowed at the young age of 52.

Mum, Jane, lived a full, varied and vibrant life for many years; as well as being a Mum to us, her past includes multiple careers; she's well travelled and had a list of hobbies as long as your arm including dancing four times a week as recently as five years ago.

Her energy would put many to shame in terms of the enthusiasm and the vitality she brought to the world. When she was younger and living in Cathays, she was actively involved in her own community where, ironically, she got pleasure from making life happier for older people.

That's all changed now. More than ten years ago memory problems beset her - and now we find our Mum with mid to late stage Alzheimer's. Still physically far better than many of her peers but without capacity to undertake even some of the most basic things the rest of us take for granted.

That's one of our biggest fears - her physical fitness makes us dread how long this cruel, savage disease will afflict Mum and of course have an effect on us and our families too.

Mum visits Oldwell Court twice a week - it's a lifeline for her. She was on a waiting list for some time. At first Mum didn't settle well but now she looks forward to going.

When she's there she's in a place of comfort; she's used to the surroundings; she's stimulated - they've even started a bit of dancing especially to encourage Jane to 'perform' and also encourage others to join in. She's built relationships with other clients, the staff and volunteers - it's taken twelve months to get to this point.

For us - we both work full time - when Mum goes to Oldwell we know she's in a place of trust; we can relax for those six hours knowing she's safe and being cared for by those who understand her; understand her needs - because they know her. We often say Mum has 'Jane Jones' Alzheimer's - that's because she's different to all the others - as is everyone with dementia.

And that's what the Alzheimer's Society people really get! Compared to the staff we encountered at the Council run day centre Mum used to attend, however well intended they were, the staff at Oldwell truly understand the ladies and gentlemen who go there and they get to know the carers too.

Mum's previously full life has made her crave company even more now - she's intrinsically lonely. We can see a time when we'll need more time at Oldwell not less. Mum's official diagnosis came in 2012 - she started visiting the memory clinic in 2005. So we had to wait nearly seven years! The figures for diagnosis of dementia are truly shocking in Cardiff - and again are so worrying. Cardiff will need far more centres like Oldwell and we believe it's the Council and Welsh Government's responsibility to deliver for its most vulnerable citizens.

Should the funding be withdrawn for Oldwell we're fearful of the massive negative impact this will have on Mum and to be honest on us too. As we've said it's taken the best part of twelve months to get Mum settled - we know moving or imposing change will see a radical decline in Mum - not only on the two days she attends Oldwell but also on the other days of the week too.

We already rely on home care provision to support and keep Mum in her own home this need will only ever increase - she's not going to get any better! The Council funds this too and we guess many others who attend Oldwell.

Can't you see that if this proposal goes ahead it will end up costing you (and the NHS) more?

Our father worked in Social Services for many years - when it was South Glamorgan County Council - he's turning in his grave now. He was devoted to protecting the most vulnerable adults. To see what's happened to public services would disgrace him and I'm sure he's looking down now thinking the same as us - shame on you Cardiff Council for getting your priorities so wrong.

We've struggled to understand the rationale behind the proposal to withdraw the funding for Oldwell.

Karen and I have responsible jobs - we both manage large projects and budgets too. We've asked to see the business case and financial justification to support the withdrawal only to be told it's not been factored to that detail yet. Why not? It's such a measly sum from the overall budget.

I'm fortunate to come into contact with many people who work with and for older people in my job at Age Cymru. I recently spoke with a Director of Social Services at another Welsh Council who quite openly told me that they're happy to reengineer the budgets if it means they can truly meet the needs of vulnerable people who are entitled to Council support.

Why can't Cardiff Council do the same?

For Cardiff Council tax payers it really does stick in the craw to hear that the Council is happy to write off £4.4m of debt to Glamorgan Cricket Club but can't find less than £200,000 a year to fund Oldwell - a vital and valuable service, supporting and serving the most vulnerable. Less than a mile from me and amidst thousands of protests; the refurbishment of a Cardiff park is going ahead at a cost of nearly half a million pounds.

"Judge a society on how it treats its most vulnerable" - really?

The Welsh Government's view of a dementia friendly Wales is being dismissed by its own capital city council's actions if the withdrawing of funds for these specialist centres goes ahead. Your proposed alternatives are nowhere near adequate for the dementia explosion that is going to happen. Your proposed actions will lead to much distress to many individuals and their families who for years have paid their Council Tax in the belief they're investing in adequate service provision for all.

From your own document:

"These proposals will be based on fairness by ensuring that the most vulnerable are least affected"

We really don't see how your proposals can possibly live up to this claim.

We also sincerely hope you and your loved ones will never be in Mum's (or our) position which is already stressful enough. Oldwell works - it's as simple as that.

Please, please think of Jane and those like her when you report back and make your vote on these proposals.

You have it in your power to and this really could be you or your loved ones.

It most definitely will negatively affect your constituents and that's who you're here to serve.

The Chairperson thanked Karen Deehan and Meryl Randell-Jones for their presentation and invited questions and comments from Members:

Members asked what the witnesses ideal model would be, and whether
Oldwell should stay as it is or be developed further. The witnesses stated that
it works as it is at the moment; it could possibly be improved by installing
hoists but it works so well due to the specialism there and that fact that service
users develop a relationship with staff who get to know their needs and how to
meet them and deal with challenges with calm, safety and love.

It was added that take a long time for people with dementia to settle into a new environment and any changes to their environment can be very detrimental.

- Members sought the witnesses perspective on the consultation process that had taken place and were advised that it was not good, they had left a meeting at Central Library feeling patronised and demoralised. It was added that they had been told notes of the meeting had been taken but were not available; they felt that platitudes had been given and they felt frustrated and that no difference would be made.
- Members asked if Oldwell Court was not an option for them, whether any other Day Centre or residential option would be viable. Witnesses stated that if they did not have Oldwell Court then the pressure they feel from the poor domiciliary care they receive would be compounded. Their mother had previously attended a Council Day Centre but it was not a good experience and their mother now refuses to go to a Council Day Centre.

The Chairperson thanked Karen Deehan and Meryl Randell-Jones for attending Committee and answering Members questions.

The Chairperson welcomed Sybil Williams and Sian Donovan to the meeting and invited them to make their presentation on Pedal Power to Committee.

Pedal Power Presentation

Pedal Power was formed in 1996 from an idea from Ely Hospital and established as a charity in 2000. In 2005 Pedal Power entered into a partnership with Cardiff Council and moved to its premises in Pontcanna.

In 2006 Pedal Power took over NHS bikes and Council cycle hire. In 2007 Pedal Power Centre became operational and was lottery funded.

Pedal Power is used by children and adults who are physically disabled and people with dementia; it provides something for everyone in the community; a positive effect on people's physical health and fitness which puts less burden on the care system.

192 people use Pedal Power on a regular basis using a variety of bike types including static bikes; there is a café which encourages social integration and wellbeing, has a positive effect on mental health and isolation. Council funding is £23k and the proposal is to cut this by £10k this year and then stop the funding altogether.

Pedal Power has expanded across Wales this year since starting in Cardiff and is leading in disability cycling.

Pedal Power can prevent future health problems; it is noted that aerobic exercise delays the onset of dementia; adults with learning disabilities use the service 2/3 times per week as part of their routine and this decreases the likelihood of them using the NHS.

Pedal Power makes a big difference in peoples lives, it's a relatively small amount of money and saves more in the longer term.

The Chairperson thanked Sybil Williams and Sian Donovan for their presentation and invited questions and comments from Members:

- Members asked whether other Pedal Power services in other authorities were funded by the local authorities. Members were advised that they had been for the first five years and that in Aberdare the service was fully funded by Adult Learning & Disability Services.
- Members asked if any NHS funding was provided to the service and were advised that it wasn't as yet although they were working on this. It was noted that they received a lottery funded programme for three years where the monies are ring-fenced for specific projects. They are trying to engage with health colleagues and show the positive impact that the service has on peoples health.
- Members suggested that due to the work Pedal Power does with autistic children, that they contact the Autistic Society to explore future funding.
- Members asked what impact an increase in price would have on existing service users. Members were advised that it would impact upon being able to use the service as often and to have carers ride with them. It was also added that the people with learning disabilities like routine and any disruption in service such as closing for the Christmas period has an impact. Therefore, there would be an impact on service users if they were not able to use the service as often because of costs.
- Members asked for the witnesses views on the consultation and were advised that they had attended a consultation meeting and been told of the cuts two weeks before Christmas; it was added that the cuts come at the same time as having to increase staff wages to the living wage which would have a negative effect on what was a growing charity.
- Members noted the good work being done and noted the challenging financial times for the Council. Members asked what other forms of funding Pedal Power receives. Members were advised that they struggle to raise funds; they do a lot of fundraising themselves, they receive lottery funding and have received Children in Need funding in the past; funding is not always continued and lots of time is spent looking for funding; not much corporate support was received and due to low staff numbers they were unable to progress exploring funding options as they would like. It was noted that if cuts were phased then they could be managed and it would give time to explore further funding options.
- Members asked how many adults with learning difficulties used the service on a regular basis and were advised 65 people used the service regularly.

The Chairperson thanked Sybil Williams and Sian Donovan for attending Committee and for answering Members questions.

The Chairperson thanked the witnesses for attending the meeting, giving their presentations and statements and for answering Members questions.

AGREED – That the Chairperson writes on the Committee's behalf to the Cabinet Member to convey their comments and observations

63 : DATE OF NEXT MEETING

The next meeting of the Community and Adult Services Committee is scheduled for 15th February 2016 at 2.00pm in CR4 County Hall.