

## **Proposal to introduce charging for non-residential care**

### **Summary of information events on 22 & 23 October and 25 November 2024**

#### **Overview**

The East Renfrewshire Health and Social Care Partnership (HSCP) hosted six information sessions (three in-person and three online) with people in receipt of a care package, their carers and family members on 22 & 23 October and 25 November.

Around 300 people attended to hear about the proposals and share their views.

Two events were hosted by Raymond Prior, Chief Social Work Officer, two hosted by Tom Kelly, Head of Adult Services: Learning Disability and Recovery and the final two by Lee McLaughlin, Head of Adult Services: Communities and Wellbeing. Each were joined by HSCP colleagues including Social Work Service Manager, SDS Implementation Lead, Carers Lead and Finance Manager. A range of staff were present in order to be able to provide answers to a range of questions.

This document provides an overview of the main themes, questions and concerns raised by attendees.

#### **General feedback**

- People wanted us to remind Cabinet that they are talking about people's lives, not money, with this proposal and that seeing things on paper and in reality are two very different things
- People are angry that the most vulnerable/people with disabilities, are once again being asked to fund the council's "black hole"
- People wanted to know if other sources of income had been considered and they challenged the Council to reconsider these plans
- There was a lot of comparisons made to the estimated saving and the spend on other council projects – attendees were upset that these projects were happening while charging was being proposed, particularly the council office renovations and bike lanes. A number of people also raised the amount of funding for schools v vulnerable people
- People expressed that ERC is not a "cash trapped" council and should be able to find this money elsewhere
- They told us the Council needs to reprioritise how it spends its money and put more into social care, particularly for disabled people
- One person made the point that while the HSCP/Council may have been impacted by inflation, that disabled people have too and the benefits they do get are there to allow them to have a fulfilling live
- There is anger that this policy will strip older people of their dignity, and money. From people who have work hard all their lives. Community Alarms costs just went up massively – when will it be enough
- One person described it as "another nail in the coffin of their pension"
- It was described as a cruel proposal that attacks the most vulnerable
- It was highlighted that young adults with autism and other challenges have a low quality of life as it is. Very often their mental health is so poor and they're in burnout and unable to keep up personal care, so these proposals are life changing to real people
- People are worried that those who need social supports will become isolated

- There were concerns raised around some people paying and others not, making it an unfair system
- There was frustration and anger about this impacting vulnerable people who get benefits because they have complex needs which require additional costs was expressed with emotion
- It was raised that if you're on benefits your children get free school meals so how can it be right for an adult with a disability who cannot work be charged for care when they get their benefits because they have additional needs or costs
- One carer said if her loved one cannot vote and therefore have a voice because of their disability, then how can they be charged for their care – it's picking on the most vulnerable
- There was frustration about this happening right after people have had assessments and already had their care reduced. They feel the timing is very poor and could have been coordinated much better which would have reduced the stress and fear this proposal is bringing
- While it was accepted that other areas charges for these services and the HSCP was applying the law, people told us that they feel this is discriminatory towards people requiring social care and the fact other HSCPs do this, does not excuse you doing it now
- People were upset that the decision to introduce charges had been made and this wasn't a true consultation
- People are concerned that £1.5m split between 600-1000 people is a lot of money for such a small number of people, all of whom are vulnerable
- A number of people asked how we reached the £1.5m figure and expressed they felt it was all based on guesses rather than facts, which isn't good enough for such a big decision
- There was frustration that there was not an exhaustive list of what is considered income and expenditure
- There was anger around the short notice of the events and the way in which people were invited
- Some questioned the timing of this when Scot Gov want to remove these charges in this term of parliament
- People asked why Elected Members who make these decisions weren't at the event to listen to people impacted directly. Others said they had written to all Ems but only 3 replied
- We were also told that staff (mainly social work) weren't able to answer questions about the proposal when they were asked which was frustrating

### **Clarifying the proposals**

- It was questioned whether it is in line with SDS guidelines for any kind of charging to take place. Our SDS lead reassured those present that it must be and all legislation and guidance will be followed
- There were other questions about SDS such as whether the policy would apply to care paid directly to providers and it was clarified that it would
- It was asked, for a young disabled adult who cannot work, what is their 'income' expected to be made up of? Officers explained benefits are included as income
- People wanted to understand if it was individuals or household income that would be assessed. Officers advised it would be the individual only except when it made sense to do otherwise, such as in the instance of a couple sharing care
- There were questions around care that is supplied by a provider, not the HSCP. It was clarified that the policy would not look at who provides the care, but who funds it.

Attendees were also reassured the policy's aim was not to reduce care, but to charge for the applicable elements of care

- People who do not have a named social worker had concerns about how this would work but social work managers were able to provide clarity for individual situations
- There was the request to define what constitutes as personal care. Staff took the time to explain this and this link to the relevant section of the legislation was shared in the chat box during the online events - <https://www.legislation.gov.uk/asp/2002/5/schedule/1>
- The definition of disposable income was also a featured topic. This was discussed and the [minimum income guarantee](#) set by the Scottish Government was highlighted. This has been set to ensure everyone in Scotland could secure a minimum acceptable standard of living and this would be included as expenditure in the financial assessment
- People were interested how the "ability to pay" will be determined and asked if disabled people would be forced to use savings similar to older people in care homes. Our finance manager outlined the proposed process but clarified a lot of detail could not be shared as this was still a proposal and processes would be determined if the policy is approved
- There were lots of questions around the proposed £20 per hour charge as people did not understand where the figure had come from. Staff explained this is not set in stone but it had been used in the modelling as it is less than the lowest cost we can purchase care for
- People asked if there will be an appeals process to the financial assessment and it was clarified there would be

### **Impact on carers**

- Carers told us they feel let down by this proposal and have lost all trust in the Council/HSCP
- Carers told us they are heartbroken for their children – some of whom have fought to stay alive and have very complex needs – and this will once again reduce their quality of life
- People stressed the upset and fear this proposal has caused the people they care for and the difficulty they have explaining and reassuring them shouldn't be underestimated
- People raised concerns about the stress this is putting on carers and question if £1.5m (a "drop in the ocean for the council") was really worth this
- Concerns it will actually end up costing the HSCP/council more money as it will be the last straw for carers who may "hand over" care of their loved one to the authority
- People expressed disappointment and frustration that carers/parents weren't involved sooner
- There are lots of pressures and demands on parent carers. They expressed that short notice of these sessions shows no care for them or genuine desire for their input
- Carers feel that decisions are being made about their loved ones care and future by social workers – and now finance officers – who don't know them and based on a 30 minute interaction. They are extremely upset and expressed this is the wrong way to do this
- Some carers feel their finances have already taken a hit due to Supporting People Framework (SPF) as they are already paying for services they believe are critical for their loved one – such as feeding and repositioning - that SPF did not categorise as critical or substantial so this is creating another wave of anxiety around finances

- Carers told us they are paying out more than ever but seeing less in return
- It was raised that this policy will push carers into poverty and depression and asked what was being done to combat this
- Carers told us they have been put through so much already and have so much on their shoulders that they just don't have the energy to keep fighting and want someone in their corner for once
- Carers feel they are being punished for keeping disabled adult children at home, as if they were in care this wouldn't apply
- It was asked what services are available to carers. Our carers lead outlined the right carers have to a support plan and the types of services available. He encouraged carers to reach out to the carers centre or himself for support
- It was expressed that no policy maker can walk in carers shoes, it's extremely difficult and they fear for their own wellbeing, and the wellbeing of the people they care for
- Carers have told us they have lost all trust of the Council and now fear what will happen to their children when they are no longer here – this point was made by a number of carers who are retired or nearing retirement with adult children with complex needs. This was highly emotional for them and a genuine concern
- There was upset that carers may have to watch the people they love decline in physical and mental health because of this/before any changes are made to their care/what they pay
- One carer told us there has never been equality or fairness with social care in East Renfrewshire for her family
- We were also told that the true impact on carers is yet to be seen and it's hard for them to think about this when the information to do this – the detail of the policy – isn't there

### **Implementing the policy**

- People expressed concern that the financial assessment will not take into consideration the costs associated with complex needs which are not always predictable or quantifiable e.g. damage to the home
- The cost of implementing this policy was questioned – how will the HSCP undertake such a large volume of financial reviews and the need to hire staff to deliver this was upsetting
- People highlighted they have already seen a strain on social work staff – long waiting times, no face to face meetings, delays with reviews, no named social worker – so questioned their capacity to deliver this
- It was raised that people have been on long waiting lists for other services – 6 months for a mental health assessment – so it's upsetting the HSCP is prioritising financial assessments, They asked if the impact this will have on other waiting lists been considered, particularly mental health
- A question that was raised a number of times was how the different elements of care would be split. HSCP staff advised that this would be down to the skill of social work staff to work with the people we support, their carers and families to establish how much of their support is personal care, and how much falls into the non-residential care. For example someone may get a 1 hour visit but of that 40 minutes is spent on personal care tasks and 20 on non-personal care tasks. It is those 20 minutes that would be in scope for charging
- People asked what the anticipated timeline for the major milestones leading up to implementation are

- One resident highlighted that when your family member has a very poor quality of life, the only thing that makes it any better is being able to do things using their "disposable" income. By taking 60% there will be a massive impact on quality of life
- Joint accounts were raised and people wanted to understand the impact this would have
- Adult mobility payments were raised a number of times and our finance manager advised these would be disregarded

### **Points requiring further consideration**

- If people are charged for services, do they become a customer and therefore do they have different rights?
- It was asked how the HSCP will monitor the impact of this policy once implemented i.e. will they survey people charged, and carers, 3, 6, 12 months into the implementation to monitor this and do this with a large sample to get quality data?
- If people are charged for an hour how will we ensure they get the full hours care – this was answered in part as our finance manager advised invoices would only be sent once information from providers on what they actually delivered was received. Although it was agreed this should be set out clearly in the policy
- It was asked if childcare would be considered in the financial assessment as some disabled people need extra support in order to parent
- Will finance officers receive training on communication with disabled people to allow them to interact with them to complete the assessments

### **Engagement process**

- A lot of the anger is at how this proposal has been consulted on and the poor communication
- People told us it's not been good enough – the letters went to people without capacity/can't read, they were sent at such short notice any people missed the events (which is why the 2 events on 25 November were arranged)
- People are upset that the people actually impacted by this proposal – primarily people with a learning disability – have not been consulted and no accessible materials produced
- The communication around the events and the proposal has been poor and people told us they only heard about it by luck, and that's not good enough for such a big proposal
- Venues – parking at both venues (Thornliebank Resource Centre and Barrhead Foundry) was difficult for people attending
- Thornliebank resource centre is not set up for these type of events and both the visuals (presentation) and sound made it difficult and the first event there just was not good enough
- Carers told us this proposal has been pushed through without true engagement
- People have said they hope any policy takes on board on what has been said and that it is fair and not just a tick box exercise
- A lot of people said the EFRIA survey link did not work for them and therefore did not get to contribute to this

## **Other feedback**

- Thank you for having this information meeting, you were able to answer our questions very satisfactorily. I look forward to further information on next steps. Thank you.
- Thanks for this discussion and for your time this evening - I appreciate it is very difficult to find a resolution to the budget shortfalls and still support those in our society who need help and let them live with purpose and dignity
- Thank you very much: I found this quite interesting and that many of the families share the same concerns. I will put forward my views/comments on the proposals
- Thank you for listening with compassion, it's not an easy message to deliver