

## **Adult Carers Voice Meeting**

**Held on 15<sup>th</sup> July 2024**

**at The Carers Centre Falkirk**

Chaired by Sharlene Ramage, Carers Centre Participation Development Worker.

Notes by Justine Wilson, Adult Carer Support Worker (Falkirk)

### **Attendees**

There were 19 people in attendance, carers with a variety of caring situations, staff and staff who are also unpaid carers.

One carer and staff member trialled a hybrid option (outcome of this experience may result in voice sessions being held both in person and online).

Bruce Leckenby Adult Carer Support – Hospital Discharge.

Magali Redding-Scottish Families Affected by Drugs and Alcohol (also an unpaid carer).

Lyn McKay- Citizens Advice Bureau.

David Miller- HSCP

Gail Aitken- HSCP

Louise McKnight- Telephone Support team (also an unpaid carer).

Jessie Ann Malcolm- NHS

### **Integrated Joint Board. Update from Carol Ann (Carers Representative) 28/6/24 Meeting.**

#### **Highlights from the Board Papers:**

##### **Agenda item 5. Chief Officer Report**

- There are a number of interim roles in place just now. Interim Head of Integration in post now and Interim Locality Manager starting Monday 1<sup>st</sup> July 2024. Head of Primary Care Leaving.
- New Chief Officer priorities are:
  - Financial resources
  - Leadership review
  - Ensuring IJB fit for purpose and can oversee sustainable services
- Some positive inspections took place and the one that needed a little bit of work was MECS but the work needed has been done so should be fine for the re-inspection.

- There is work planned for “Your Home First”.
- There was some discussion about hospital discharge, which I raised initially under the Chief Officer report.

#### **Agenda Item 6 & 7 – Chief Finance Officer Reports**

- The CFO is new in post and advised the Board she would be reviewing what currently comes to IJB in the Finance papers with the plan of providing more detail in the future.
- Discussion about using funds for transformation in relation to Cunningham House.
- Work around early intervention and prevention. Ongoing for people to be able to stay at home, but this work could take anywhere from a few months up to a year.
- Agenda for Change is having a knock-on effect on services (this is related to the reduced weekly hours for NHS staff – all dropping 30 minutes of their working hours per week).

#### **Agenda Item 8 – Proposed Integration of Children’s and Justice Social Work Services with Falkirk HSCP**

Paper from the Chief Social Work Officer and Head of Integration on the integration of above services. Someone from a Union said the staff don’t welcome this integration and don’t feel it is required. I was able to confirm what I had said at the development day, i.e. that carers do welcome the integration as it will allow for better transitions and hopefully lead to not having to explain your circumstances every time.

#### **Agenda Item 10 – Alcohol & Drug Partnership Annual Reporting Survey 2023/24**

A report was provided to the IJB and under this item I was able to say that more comms around “My Family, My Rights” programme would be helpful.

#### **Agenda Item 11 – Communication Strategy & Participation and Engagement Strategy (2024 – 2027)**

#### **Agenda Item 13 – Communication Update**

This strategy was put forward for approval of the Board, which was granted, and the usual communications update was also put forward (standing item on agenda).

I managed to cover a few communication issues in the meeting (have put these at end).

#### **Agenda Item 12 – Forth Valley Mental Health & Wellbeing Strategic Plan**

The plan was put forward for Board approval. There was discussion about people not wanting to be in a “group” to talk about their mental health and focussing more on a preventative approach.

Under this item I was able to raise the positive feedback for Kasia, the new Social Care Officer who started in April 2025. I was also able to carer feedback. I was then able to catch Martin Thom at the end of the meeting - who was responsible for signing off the budget for the new Social Care Officer post - and let him know how much positive feedback is being received about Kasia, but as this was a pilot role, there was concern from carers that as she is the only one doing this job and she may have to spread herself too thin.

I was able to let the IJB know about the positive Strathcarron Hospice experience under this agenda item.

I did highlight to the IJB here, that when things are not being done properly for carers (such as hospital discharge), then it affects the carer’s own mental health and wellbeing.

### **Agenda Item 13 – Performance Monitoring Report**

Under this item, there was a discussion about delayed discharge, and this will be discussed further at the next meeting. The GP representative had a lot to say about hospital discharge generally but also in respect of delayed discharge as well as the concern about readmissions. GPs are not being kept in the loop about discharge which has a knock-on effect on the care to patients as things are getting organised too late.

### **Other Carer feedback I managed to share at this meeting:**

Hospital Discharge: during the meeting (mostly at Agenda Item 5) I was able to share that carers are:

- not being identified in hospital in line with legislation
- unaware they can ask for a discharge plan
- not aware of the carer support that is available
- that there are only two Carers Centre hospital staff covering all of Forth Valley, so not all carers able to access support/that they should be getting referred to the hospital support workers - but still not being involved in discharge planning as they should be
- mentioned that since Covid there are no leaflets and would it be possible to put messages on the TV screens in waiting rooms

Information sharing: I had the chance to mention that information sharing is often challenging for carers and referred to things like treatment or specific medications that affect carers after discharge, but data protection makes that difficult for carers.

Consultations and Feedback: I also had the opportunity to mention that when consultations are carried out and feedback is requested (e.g. Oswald House) then carers want to hear outcomes as currently they feel that they feed back and feel not listened to because they don't then hear anything.

### **Sharing of Information**

Sharlene shared with everyone information about upcoming Alzheimer's Scotland events and the new Caring with Confidence sessions.

Carol Ann and Sharlene have been invited to attend future Carers Cross Party Groups at the Scottish Parliament- first session is in September, a great opportunity for Carol Ann to share carers views at parliamentary level.

Carol Ann has been invited to meet with the Acting Head of Integration to discuss hospital discharge on the 26th of July, Carol Ann will keep us posted.

### **Lyn McKay Citizens Advice Bureau.**

Lyn spoke about upcoming changes to benefits, emphasising the importance of carers migrating to these new benefits to ensure they do not lose any benefits.

Lyn also spoke about the new carers support payment which will replace carers allowance and how carers will not need to do anything as they will automatically change to this.

Students can now apply for Carers allowance which is a welcomed change.

Carers shared that they are frustrated that they cannot claim Carers Support Payment and State Pension at the same time, (private pension is ok). Sharlene will meet with Lyn to discuss ways that we can possibly raise carers views, Sharlene will keep carers informed of progress and invites carers who have personal experience of this to share their experiences with Sharlene, via phone call, email or coming into the centre (please get in touch). Lyn seconded that the more input we have from carers regarding their experiences, the more power we have to ask for change.

Lyn spoke about working carers and how working over 12 hours can result in carers losing benefits (Carers allowance and possibly some Universal credit). Discussion was had around carers feeling that they are encouraged to work, and many want to continue working but the system is not supporting them to do so (again personal experience would be welcomed).

Discussion around council tax and exemptions. Discussion around benefits forms and carers finding these forms being very long and complicated to complete.

Attendance allowance will change name in the near future, (not just name, but to devolved benefits SSS and called Older adult payment support) carers will receive a letter regarding this, the person in receipt of this allowance must complete the form and return this or this benefit will be stopped, Lyn shared her concerns about people with a dementia diagnosis not opening their letter and having their benefit stopped.

A carer asked if carers could receive carers allowance when the cared for person is in a care home, Lyn said that this is not possible, however the cared for person can apply for pension credit. (Carers allowance will stop once the cared for becomes a permanent resident or in the facility for 4 weeks and pension credit can be applied for where applicable)

### **David Miller HSCP**

David came along to tell carers a little about Falkirk Carers Strategy. There was discussion around short breaks and self-directed support, with many carers keen to find out more. A parent carer was keen to discover more about flexible respite and if parent carers can access this support, David informed the carer that this is something that children's services are currently reviewing, this carer was very keen to hear more from children's services about their plans for parent carers accessing flexible respite. David said he will try to find out more information for the carer and it was agreed that Bruce would share the carers information with David who would contact the carer directly.

Some carers shared their experiences that although they have been allocated respite hours, they cannot find suitable respite provision for their loved one.

Carers shared their experiences of public transport and the lack of accessible services. David said that this is a separate entity as transport has its own policy.

A carer asked David which care homes have availability and how many spaces there are in each, David said that there are 4 council operated homes and Gail advised of some care homes that she knows are currently used by Falkirk Council at the moment, the vacancy list comes from Falkirk Council.

### **Some of the Carers' Situations/Views**

- One carer that cares for her children shared her experiences of the benefits system and how she is now receiving £600 less per month, (due to separating from her partner and downsizing her home), savings in her bank now means she is not eligible for some benefits that had previously been a life line for her, carer has had to reduce her working hours due to stress and fears that she will no longer have money for emergencies ie car breaking down. This carer has emailed her experience to Sharlene and provided consent to share, Sharlene and Lyn will meet soon to discuss the best way to raise this.
- Many carers feel that the government is making it harder for them to seek or maintain employment, due to benefits being stopped when carers are only earning less than £200 per week.
- Many carers felt that it would be beneficial to receive Carers Support Payment when they are in receipt of State Pension.

- Jessie Ann Malcom suggested taking carers views regarding benefits/ state pension to the coalition of carers and Sharlene suggested that this might be something that Carol Ann and Sharlene can raise at the cross party in September (Parliament).
- Carer cares for husband who has Parkinsons and is an amputee, this carer said that respite is very hard to arrange, she had booked a holiday and had to change the date as she could not access suitable alternative care for her husband, carer is keen to find out more about flexible respite.
- Carers discussed the lack of accessible transport, very few taxis can accommodate wheelchair users and buses only have one bay for a wheelchair user, this space is shared with pram users and many carers feel this is a barrier to them accessing community resources. We also discussed rural areas where one bus comes an hour and how carers/cared for people are not able to get onto the bus if a wheelchair user is already in this bay.
- Carers mentioned Dial-a-journey and how this service is great but hard to access at times due to lack of available spaces and need to book in advance.
- Jessie Anne asked carers in the room if she can attend monthly meet ups as an unpaid carer and professional, there were no objections in the room.
- Carer felt strongly that her "sons' money is taken as hers", suggestion from carers in the room for the carer to open a joint bank account, carer is concerned about continuing to care.
- Carers suggested for the voice in the future short breaks and flexible respite and MECS.
- Parent Carer advised that she has been on a waiting list for 6 years for respite and feels that the lack of respite for parent carers and other parent carers feels "very bleak".
- Discussion around cared for people and access to provision/support when cared for persons dementia has progressed, some carers are concerned that there are very limited resources for people when they are in advanced stages of their dementia journey.

Looking forward to seeing you all at the next voice! Many thanks, Sharlene.