

**Learning Disability Carers Consultation  
Thursday 21<sup>st</sup> November 2013**

**Consultation Report**

## **1. Purpose**

The purpose of the consultation was to gain knowledge of what carers thought of existing Learning Disability Services that the person they were caring for was receiving, and if it could be improved.

It focussed on-

- How they can exert more influence on care planning and the nature of the services they use.
- How the services can be more individually tailored to their needs.

This event was for carers of service users with a learning disability and was split into two sessions.

## **2. Method of Consultation**

The feedback from previous consultations was that the carers wanted to be part of the service user consultation but also would like the opportunity to have a separate consultation.

The event was held in the Burgh Hall, Dumbarton and was an all day event for the carers. 150 carers were invited to the event and 25 attended on the day.

The consultation was split into two sessions as follows-

Morning session-took place in conjunction with the service user consultation and involved three scenes performed by “The Good Life” drama group. After each scene there was an opportunity for discussion and feedback which was then recorded by the table facilitators.

Afternoon session-for carers this took place in a separate area and focussed on two topics that had been identified through returned questionnaires. These were Self Directed Support and Independent Living Fund.

## **3. Topics of Discussion**

The theme of the day was “have your say” with different topics on how to help people make changes and raise issues about the service/support that they receive. The scenes performed by the Good Life Group came under the umbrella of “Ah’m no happy”.

### **Morning Session**

**Scene 1**-Service user not getting the chance to take part in an activity of their choosing as the support worker does not want to take part. Following this scene the comments and suggestions from carers included-

- Better Care Planning
- Better communication via provider

- Service provider/manager should be approachable (to service user and worker)
- Support Worker has to be confident and competent in many activities
- Carers' need to be confident that their relative is safe
- Responsibility is on the worker to raise issues that is affecting the service user
- You need to have the flexibility to change provider if all else fails
- More interaction from team leaders all year round not just annual review
- Matching up is very important
- Support Workers must build support and confidence of the service user to avoid conflict
- Non-verbal users needs - understand body language and symbols
- Keep service users diary up to date
- The need for appropriate staff
- Reviews
- Pool of carers
- Not enough staff
- Carer should identify problems/issues
- Good training for carers to help them identify issues
- Not to look at concerns as complaints
- Need to make time to communicate

**Scene 2-**Overcoming differences between carer and service user i.e. carer not keen for son to attend college due to concerns of risk to son. Following this scene the comments and suggestions from carers included-

- Parents and relatives are protective
- Good communication within family/group, communication is key
- Carers need to know where to go to discuss issues/possibilities
- Concerned because stigma is still there
- Lots of planning, back up plans, find a supportive college
- It's about carers taking the time to do these things
- Parent peer support
- If support or buddy (going to college) is not in place it affects life in the future (lost confidence)
- Transition from child to adult needs more support
- Liaison person at college
- Build up confidence for user
- Main stream schools should take more responsibility in transition
- Up to date contact list for support
- Updated carers' assessments
- Regular, up to date information leaflets

- Find out if the course is actually suitable for the service user
- Get all your facts
- Good understanding of safety issues (open to adaptability)
- Good to try new things/outside your comfort zone
- Parents may need support
- Possibly it's the parents who need the support rather than the service user

**Scene 3**-Worker cancelling at the last minute. Worker not putting enough importance on sticking to agreed appointments with service user. Following this scene the comments and suggestions from carers included-

- Trying to have an allocated social worker in the first place is the difficulty
- You get good and bad workers
- Guardianship means I see my son's Social Worker at least every six months
- You need a named person that already knows your situation and a relationship has been built on
- Good communication, keeping the lines of communication open
- The importance of reliable up to date contact details
- To be kept well informed by our social worker of any changes
- Flexibility of social worker
- Lack of funding and budgets puts extra pressure on service delivery
- keeping the lines of communication open
- No continuity of service
- Social Worker changing all the time has a negative impact

### **Afternoon Session**

#### **Information Pack**

Each carer in attendance was given an information pack which consisted of a programme of the afternoon, booklets on the local carer support service, leaflets on Power of Attorney and Guardianship.

#### **Quotes Board**

There was a quotes board placed around the room. This consisted of quotes from returned questionnaires that were sent out to carers, prior to the event. Some of the quotes captured were-

“A dedicated website with all learning disabilities services should be available and updated regularly”.

“Make people aware of what services are available, rather than relying on them knowing what to ask for. Ensure staff communicates with families in a transparent manner”.

“All service providers should keep carers informed of any updates or concerns about (a care plan)”.

“Communication and reviews are so important (in a care plan)”.

A discussion took place around the content on the Quotes Board, and it was agreed that the common theme was effective communication from all parties, carer, service providers and service users.

This would ensure that everyone is informed and involved, with any changes and updates recorded on the Care Plan.

From the returned questionnaires, a high level of carers wanted more information on Self Directed Support (SDS) and Independent Living Fund (ILF).

These were the topics of discussion for the afternoon session, this was delivered by Margaret Reid and Vicky MacKenzie WDC – ILF, and Furrar Arshad RNIB – SDS.

### **Independent Living Fund**

Joanne opened the afternoon session with introductions and an overview of the topics to be discussed.

The first presenters were Margaret Reid and Vicky MacKenzie, discussing the changes to ILF. It was explained that there seems to be some mixed messages around the changes to be made to ILF, and that 5 independent people took the decision to end ILF to court. There is currently a court case underway regarding this, and until this is concluded, nothing is as yet finalised.

Department of Works and Pensions (DWP) have also still to “cross the T’s and dot the I’s”

Margaret also stated that transfer reviews are now not legal for the people who have had them, people are still due reviews and things are changing every day. It was also stated that we should still have a date of 2015 in mind of when this should come into effect.

A discussion then took place regarding the end of ILF and the worry of mixed information from Government to Scottish Government to local authority and that it may not all flow down.

One carer commented on ILF being a two tiered system and is unfair, and hoped for a full transfer.

The up and coming referendum was also discussed and how this may affect SDS and ILF.

Margaret said that she would be happy to come out and meet everyone one to one to help advise with the transfer.

### **Self Directed Support**

The second discussion was around SDS and this was presented by Furrah Arshad.

Furrah explained the concept behind SDS, and how it will allow people more choices when deciding on their care. There are 4 choices you can make when using SDS;

1. Direct Payment
2. The person directs the available support – Could be an external provider used.
3. Local authority to arrange support
4. Mix of above – More person centered

Furrah went on to explain why SDS is being introduced, that it's an opportunity to meet the assessed needs of each individual, allows for transparency and openness and allows services received to be fit for purpose.

SDS is initially being piloted over 3 groups;

1. Adults with Learning Disabilities
2. Older People with Learning Disabilities
3. SEN children in transition.

The aim is to increase awareness and that everyone is involved and consulted with. Also it is important to raise awareness with service providers, as this will allow more flexibility.

After April, the local authority will look at evaluating the progress.

At this point, a questions and answers session started;

**Q** – Is there a budget being set aside for Telecare?

**A** – Yes, there will be a separate budget for this.

**Q** – Is SDS being used to cut budgets?

**A** – The budget wouldn't change if your needs haven't. Glasgow used a points system but WDC are not using this system and instead is using an individual framework banding.

**Q** – Is there any negative effects of SDS?

**A** – If SDS doesn't work for you, you can stay the same and maintain the status quo, but would encourage lots of consultation.

**Q** – Can a P.A be a member of family?

**A** – No blanket rule to say no, will be looked upon on an individual basis, local authorities are expecting guidance on different rules and how we will put this into our procedures.

Discussions then took place around employing family members, and that this may not be the best support for the service user, and would have to be addressed on a case by case basis. Dealing with employment issues with a family member may be more difficult, and could make communication more problematical.

It was highlighted that there will be a period of adjustment until people are comfortable with the right level of self-support.

At this point, talks began around Guardianship and Power of Attorney, with many questions being raised around this and certain issues relating to SDS, Joanne asked if everyone would like a separate information day around these subjects as the discussions would be quite lengthy, and would like to give it the appropriate attention, everyone agreed, and Joanne confirmed that a date would be sent out to everyone for a half day event at the carers centre with expert speakers to answer everyone's questions.

There was also a "Thoughts Board" where participants could write down on post it notes their views and opinions on other subjects that may be of interest or concern to the carer.

#### **4. Results of the Consultation**

Following analysis of the feedback from all participants, the findings of the consultation event are as follows:

The event was well attended, with plenty of discussion and questions around the topics on the agenda.

It was agreed that the common theme from the Thought Board was effective communication from all parties, carer, service providers and service users. This would ensure that everyone is informed and involved, with any changes and updates recorded on the Care Plan.

The carers in attendance highlighted some concerns they had around the ending of ILF, and the changes SDS will bring when it is introduced. Although a lot of these concerns were addressed during discussions, it was agreed that further discussions would have to take place for individual questions, and this will be arranged by the Carers Centre.

**Appendix 1  
Invitation Letter**

**Director; Keith Redpath**

Learning Disability Service  
Beardmore Business Centre  
9 Beardmore Street  
Dalmuir  
G81 4HA  
Telephone No: (0141) 562 2333  
Fax No: (0141) 562 2323  
Date: 19/09/2013

Dear

We would like to invite you to come to a consultation event on Thursday 21<sup>st</sup> November 2013 at Dumbarton Burgh Hall. This is an opportunity to discuss how we can support service users to:

- Empowering service users to make choices about the services they receive
- Empowering service users to make changes to services they are not happy with

**Registration: 09:30**

**Start: 10.00 a.m.**

**Lunch (provided) 12:00 p.m. – 1.00 p.m.**

**Finish: 3.00 p.m.**

Service Users Consultation is a half day event also on November 21<sup>st</sup>.

We are also keen to hear views and opinions on other subjects that are of interest or concern to you as a carer.

Please select **up to 2 topics** from the list overleaf. Your views are very important to us. If you are not able to attend the Consultation please fill in the attached questionnaire.

I would be grateful, therefore, if you would telephone 0141 562 2333, to let us know if you plan to attend. Alternatively, you may complete the attached slip and return it in the stamped addressed envelope.

Yours Sincerely,  
David G. Elliott  
General Manager

## **Appendix 2 Discussion Guide**

**Carers Consultation**  
**21<sup>st</sup> November 2013**  
**Facilitators Notes**

9.30am – 10.00am – Registration, tea and coffee

10.00am – 10.15am – Opening remarks

10.15am – 11.00am – Good Life Group

*This is broken down into 2 sections, each section will show a sketch from the Good Life Group, lasting approx. 5 minutes, followed by a 15/20 minute roundtable discussion.*

**What do carers think about having their say?**

**Pointers for Facilitator**

- Clear communication from service user – carer- service provider
- Update of care plans
- Service user needs being met with the help of communication

**What do carers think about overcoming differences between carer and service user?**

**Pointers for Facilitator**

- Balance between keeping service user safe, but allowing room to develop
- Communication between carer and service user to highlight safety concerns

11.00am – 11.15am – Comfort break

11.15am – 11.45am – Good Life Group

*This is broken down into 1 section showing a sketch from the Good Life Group, lasting approx. 5 minutes, followed by a 15/20 minute roundtable discussion.*

**What do carers think about communicating effectively?**

**Pointers for Facilitator**

- Would you know what to do if you feel you haven't been listened to?
- Who is the right person to speak to

- **Service impact**

11.45am – 12.00pm – Closing remarks

12.00pm - 12.45pm – Lunch

12.45pm – 1.00pm - Brief explanation of “Quotes Board” with an invitation for carers to read the quotes, and also the opportunity to add more if they wish. These will be used in the final report.

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1.00pm – 1.45pm – Discussions around Self Directed Support (SDS) and Independent Living Fund (ILF).

Presented by:

Margaret Reid – ILF (CHCP)

Vicky McKenzie – SDS (CHCP)

Furrah Arshad – SDS (RNIB)

**Presentation, and open discussions around these topics.**

1.45pm – 1.55pm – Comfort break

1.55pm – 2.30pm – Continue discussions around Self Directed Support (SDS) and Independent Living Fund (ILF).

Presented by:

Margaret Reid – ILF (CHCP)

Vicky McKenzie – SDS (CHCP)

Furrah Arshad – SDS (RNIB)

**Presentation, and open discussions around these topics.**

2.30pm – 3.00pm – Summary and Evaluation

Thank you, evaluation form, inform carers of report of consultation.

3.00pm - Finish

### **Appendix 3 Questionnaire**

## Carers Consultation Questionnaire

Q1. As a carer, are you happy with the existing Learning Disability Services that your family member/loved one receive?

Yes

No

Unsure

Q2. If you have a query or concern regarding the service your family member/loved one that you care for receives, would you know who to go to?

Yes

No

Unsure

Q3. If you answered no to question 2, please tell us how we can make this easier for you.

Q4. As a carer, have you ever felt that the care plan for the person you care for needed changed because it was not meeting their needs? If so, did you know how to go about this?

Yes

No

Unsure

Q5. If you answered yes to question 4, how easy was the process to make these changes?

Very easy

Easy

A bit difficult

Very difficult

Q6. As a carer, what do you think we could do to help to make the process of changing someone's care plan easier.

Q7. Do you feel there is adequate information out there regarding the Learning Disability Services provided by Social Care and Health?

Yes

No

Unsure

Q8. If you answered no to question 6, please state below what you think we could do to provide more accessible information.