

## **West Dunbartonshire Council**

### **Draft Response to Consultation on Draft Guidance for Respite Care**

#### **1. What are the main strengths and weaknesses of the draft guidance?**

A strength would appear to be that the guidance attempts to be inclusive and cover all client groupings from children to adult services. This could be a weakness in that the guidance may be too broad, in trying to achieve guidance across very wide groups with diverse needs. There may be a benefit from a more streamlined approach for specific client groups?

The three main outcomes stated by the Scottish Government reflect the provision of respite services for people within West Dunbartonshire Council and most likely most local authorities.

A key to the document is the definition of respite and the importance of the **purpose** of respite rather than not what type of service is provided. At present the definition provides a comprehensive listing of the various different ways of delivering respite and short breaks, however the definition would benefit from highlighting the purpose of respite a bit more than it currently does – would therefore suggest having the purpose stated first as paragraph 1 and then describing means of providing respite as paragraph 2?

With reference to paragraph 14 - Does the present consultation exercise on the Looked After Children (Scotland), Regulations, 2008 impact on this Guidance?

There are funding issues around ongoing affordability, for the funders of respite care, of increasing demand/need for respite care while providing clients and carers with greater choice and flexibility. It is clearly stated that the agreed direction for respite provision is to more choice and flexibility and this within a background of people living longer is bound to result in additional cost. The guidance does not really address this issue.

#### **2. What if anything is missing?**

The guidance highlights that respite is effective in “preventing social isolation –providing a break from their usual routine for people with care needs and carers, enabling them to take part in leisure or other activities.”

What is not included is the importance of respite in maintaining friendships particularly for young adults during the time of transition into adult services when they can loose touch with friends from school. This should be included.

The ideas, preferences and experiences of people within West Dunbartonshire has emphasised the importance of flexible respite i.e. the opportunity of holiday breaks, or breaks at home alternatives to Traditional

Residential Respite, this has been recognised by West Dunbartonshire Council.

An issue relating to “Flexible Respite Services” is that the increasing number of service users can compromise aspirations such as those above.

An increasing number of people with learning disabilities and/or physical disabilities are living into older age with a range of complex health needs.

In 2004-2005 there were 1,348 nights Traditional Respite (Respite Breaks in supported Accommodation) used. This increased to 1,755 nights in 2006-2007.

With the increases and demand for respite as above with limited resources a “model flexible respite service” can be difficult to uphold.

### **3. Is the Terminology clear?**

The terminology is relatively clear, however it does vary across the guidance document – would suggest some definitions as to the terms used throughout should be included at the beginning of the document.

### **4. Strategic Planning - Does the draft guidance cover the most important factors in relation to the strategic planning of respite services**

Yes, however some comments on this section as follows:

The benefits of respite for clients identifies a need for self-advocates to enable people to have control, offer good experiences and personal advantages. Where better to receive information regarding respite than straight from the individual receiving the service. An advocacy service is important for successful involvement of clients and carers. There should be reference to advocacy as being of strategic importance within the guidance.

In the section entitled “Types of respite” it is further detailed that the aim should be to provide clients and carers with greater choice and flexibility. As indicated above, in response to section 2, with increasing demand/need for respite services there are issues around longer term funding of ever expanding and flexible service provision.

### **5. Information Provision - Does the guidance cover the main aspects of information provision relating to respite? Are there additional examples of good practice which would be valuable to include;**

The guidance does cover the main aspects of information provision, however comments as follows:

Paragraph 32 refers to “Respite Bureaux” – it is important to note that in many cases such facilities are not necessarily called this, often called carers service and may be provided through an advocacy service. The guidance should

state that the establishment of a “Respite Bureau” or more than one should be good practice and that respite funders should attempt to facilitate this.

As noted in response to item 4 (above) it is important for an independent Advocacy Service to be available to clients and carers in order to access independent information.

Examples of good practice within West Dunbartonshire Council include:

- The employment of a Learning Disabilities Services Respite Resource Worker has assisted in the assessing, monitoring, and providing of information for carers and clients when accessing the service.
- Planning the development of the respite service has included consultation with a number of carers and client groups. This includes the Respite Steering Group made up of carers of Adults with Learning Disabilities receiving respite. This group is assisting, guiding and advising in the building of a 6 bedroom purpose built respite service within West Dunbartonshire planned for 2008.
- Establishment of an independent advocacy service.

**6. Eligibility - Are the suggested criteria and risk factors relevant and comprehensive**

Yes these are relevant and comprehensive – see comments below regarding Annex C.

**7. Annex A : Indicators of Good Respite - Is the list relevant and comprehensive**

The particular indicator of good respite: “able to maintain or improve the well-being of the care recipient” should include the **carer** in this indicator.

Further indicators of Good Respite should include:

- “able to sustain peoples significant relationships, encourage/support one to one relationships to evolve”;
- “able to respond to ideas and concerns of service users and carers ensuring attention to detail”; and
- “Flexibility – ability to be flexible in providing options of the type and length of respite available”.

**8. Annex B: Examples of Good Practice - Are the examples relevant and useful? Can you suggest similar examples**

The examples provided are relevant and useful some comments:

### Breaks At Home

A break at home can also increase confidence for a service user in other kinds of respite. With staff consistency, the importance of one to one support can build relationships and inspire confidence in an individual to move onto a different break e.g. a supported holiday break with the worker who has been providing the support during the break at home.

With this kind of development the carer is able to have a break from their caring role at home.

### Providing equipment or adaptations to facilitate respite

Agree with this example, but would seek to add a comment about the provision of emergency alarms or other form of Telecare, which can also build confidence in both the service user and the carer that appropriate assistance can be provided during respite periods (and during normal periods).

### Respite in Supported housing

Agree with this example, but would seek to add a comment regarding “Step up/Step down facilities within such housing. Such facilities can also be used for respite where the service user has a high level of dependency.

### Respite for carers of people with a terminal illness

West Dunbartonshire Council runs a service specifically targeted at people suffering from cancer in partnership with Macmillan Cancer Support. This is an example of good practice.

## **9. Annex C: Respite Needs of Specific Groups - Are those in the draft relevant and useful? Can you provide similar details for the other groups listed.**

Yes these are relevant and useful, however some comments:

- i) Being a carer in any circumstances is a difficult and challenging role this should be clearly stated within the guidance and within Annex 3.
- ii) Suggest adding a new group “Carers with terminal illness” - In addition to the group mentioned “Carers of people with a terminal illness” with the following comments regarding this new group:

“Carers and service users require more regular breaks, respite can be valuable in preparing for the future with specialised service involved.”

- iii) Suggest further comments regarding Older Carers as follows:

“Older carers have their own health and social support needs. Older carers worry about the future and what will happen when they are not able to care. Respite is valuable in helping an older carer and the service user prepare for the future.

Carer’s assessments are particularly important to older carers as they include all the details of the caring role and how it affects them.”

The role of carer may even be taken on by the person with the learning disability.

- iv) Would also suggest an additional client group: “People with Profound and Multiple Disabilities”, with the following comments regarding this group:

“The needs of people with profound and multiple disabilities and their carers are wide with the number and range of daily care responsibilities substantial with the average carer being woken 3 times a night. Respite can be valuable in assisting the main carer and family to sustain these levels of care day after day, night after night. People with profound and multiple disabilities have specific requirements that call for specific respite needs.”