**Appendix 2** – Interview guide active family caregivers

**Interview Guide for Active Family Caregivers**

**Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A Qualitative study**

**Background**

Thankyou for agreeing to take part in this face to face interview. I will be asking you questions that relate to your experience as a family caregiver, they will help enable me to identify what informational needs existed for you and what health care services could do to help. The interview should last between 40-60 minutes and will be audio recorded with your informed consent.

Can you start by telling me a bit about your family member’s current medical/health status?

**Prompts:**

* How long have you been providing care for your relative/spouse/friend?
* How did you feel when you were told the person you care for had developed an illness that required palliative care?
* How do you feel generally about the palliative care and support your relative/spouse/friend has received?
* How do you feel generally about the care and support that you have received to date as a family caregiver?

**Information about the patient**

Can you tell me about any verbal or written information you received on your relative/spouse/friend’s illness?

**Prompts:**

If yes –

* Who provided you with this information and how was it delivered?
* What types of information and education did you find most helpful?
* What further information would have helped you?

If no –

* What information and education do you think you would benefit from having?

**Information about the family caregiver**

Were you provided with any information to prepare you for your role as a caregiver and would it would entail?

**Prompts:**

If yes –

* What type of information did you receive?
* Who provided this information?
* Do you feel there was any other information that would have helped to prepare you?
* In what form do you prefer to receive information? (verbal/written/internet/mixture)

If No –

* What types of information do you feel would help to prepare you in your role as a caregiver?
* In what form would you prefer to receive information? (verbal/written/internet/mixture)

**Information on Practical Support**

Can you tell me about any information you were given to help you practically with the care of your family member? (i.e Home care workers, equipment, advice)

**Prompts:**

If yes -

* How were you provided with this information?
* Can you tell me about how the information you received enabled you to get practical support?

If no-

* What practical support do you feel you need to help you in your caregiving role?
* What information do you think you would benefit from in relation to practical support?

**Information on Social Support**

Can you tell me about any information you may have received about social support such as respite or support groups?

**Prompts:**

If yes –

* What services where you informed of?
* Who informed you of these services?
* What do you, as a caregiver, find most beneficial?
* Can you tell me about any extra information you may have received from palliative care services, on social support, from the palliative diagnosis was made?

If no –

* What do you think you think stopped you from receiving information on social support?
* How do you feel you would benefit from social support?
* What information do you feel you require to be best supported socially?

**Information on Financial Entitlements**

Can you tell me about any information you may have received about benefits or financial support you may be entitled to as a caregiver?

**Prompts:**

If Yes –

* Who provided this information?
* How were you able to access the financial support you were entitled to as a result?
* Can you tell me about any problems you encountered?

If no-

* What information do you feel you would require to be best supported financially?

**Information on Psychological Support**

How do you feel you are coping emotionally in relation to your relative/spouse/friend requiring palliative care?

Have you received information on emotional, psychological or spiritual support?

**Prompts:**

If yes –

* What type(s) of information did you receive?
* How were you able to access this?

If no –

* What kind of emotional, psychological or spiritual support do you feel would be helpful?
* How do you feel this would be best delivered (face to face/written/internet/mixture)?
* What information do you feel you would require to enable you to access this emotional or psychological support?

**Care-Giving Experience and Involvement**

How have you found caregiving general?

**Prompts:**

* What aspects of caregiving do you find satisfying?
* What aspects of caregiving do you find difficult?
* Can you tell me about how you have, or have not been included, as a carer, in decisions about your family member?

If yes –

* How have you been included? - For example can you describe how services have worked in partnership with you?
* What could be done better?

If no –

* How could you have been more included?
* What do you feel has prevented this?

**Experience of Services**

Can you tell me about new or additional services that you have, as a caregiver, received since the diagnosis of this palliative illness?

**Prompts:**

* What professionals have been or are involved?
* Can you tell me about any support you have received from learning disability services?
* Can you tell me about any support you have received from palliative care services?
* What information and support did you find the most beneficial?
* Is there anything that you felt did not work well?
* Was there anything missing from the services you have received?
* Do you have any more thoughts on information that would improve support for caregivers of people with learning disabilities who require palliative care

Are there any other points you feel are important to raise?

* If a programme to provide information and support for family caregivers of people with learning disabilities at end of life were to be developed how do you think this could best be delivered so that family carers could have access to it?
* Are there any other comments that you would like to make about information and support for family caregivers of people with learning disabilities

**Thank you for agreeing to take part in this interview and for giving your views and time. It is much appreciated.**

**Appendix 2** – Interview guide bereaved caregivers – version 3



**Interview Guide for Bereaved Family Caregivers**

**Determining the informational needs of family caregivers of people with learning disabilities who require palliative care: A qualitative study**

**Background**

Thankyou for agreeing to take part in this face to face interview. I will be asking you questions that relate to your experience as a family caregiver, they will help enable me to identify what informational needs existed for you and what health care services could have done to help. The interview should last between 40-60 minutes and will be audio recorded with your informed consent.

Can you start by telling me a bit about your relative/spouse/friend’s illness?

**Prompts:**

* How many years had you been providing care for your relative/spouse/friend?
* How did you feel when you were told the person you provided care for had developed an illness that required palliative care?
* How do you feel generally about the palliative care and support your relative/spouse/friend received?
* How do you feel generally about the care and support that you received as a caregiver?

**Information about the patient**

Looking back do you feel you were able to find out all that you had wanted to know about your relative/spouse/friend’s illness, verbal or written?

**Prompts:**

If yes -

* How do you feel about the information and education you received on the illness, throughout the time you were a caregiver?
* Can you tell me what types of information and education you found the most helpful?
* How were you able to get this?

If no –

* What information and education do you think you would have benefited from having?

**Information about the family caregiver**

Were you ever provided with any information to prepare you for your role as a caregiver and would it would entail?

**Prompts:**

If yes –

* What type of information did you receive?
* Who provided this information?
* Do you feel there was any other information that would have helped to prepare you?
* In what form do you prefer to receive information? (verbal/written/internet/mixture)

If No –

* What types of information do you feel would have helped to prepare you in your role as a caregiver?
* In what form would you have preferred to receive information? (verbal/written/internet/mixture)

**Information on Practical Support**

Can you tell me about any information you were given to help you practically with the care of your relative/spouse/friend (i.e home care workers, equipment, advice)?

**Prompts:**

If yes -

* How were you provided with this information?
* Can you tell me about how the information you received enabled you to get practical support?

If no –

* What practical support do you feel you would have needed to help better care for your relative/spouse/friend?
* What information do you think you would have benefited from in relation to practical support?

**Information on Social Support**

Can you tell me about any information you may have received about social support such as respite or support groups?

**Prompts:**

If yes –

* What services where you informed of?
* Who informed you of these services?
* What did you, as a caregiver, find most beneficial?
* Can you tell me about any extra information you received from palliative care services, on social support, from the palliative diagnosis was made?

If no –

* What do you think you think stopped you from receiving information on social support?
* How do you feel you would have benefited from social support?
* What information do you feel you would have required to be best supported socially?

**Information on Financial Entitlements**

Can you tell me about any information you may have received about benefits, or financial support you may have been entitled to as a caregiver?

**Prompts:**

If Yes –

* Who provided this information?

How were you able to access the financial support you were entitled to?

* Can you tell me about any problems you encountered?

If no-

* What information do you feel you would have required, to have been best supported financially?

**Information on Psychological Support**

Did you receive any information or guidance for emotional, spiritual or psychological support during your relative/spouse/friend’s illness including the final stages and in your bereavement?

**Prompts:**

If yes –

* What type(s) of support were you provided with?
* Can you tell me how you were able to access it?

If no –

* What kind of emotional, spiritual or psychological support do you feel would have been helpful?
* How do you feel this would have been best delivered?
* What information do you feel you would have required to enable you to access this support?

**Care-Giving Experience and Involvement**

Can you tell me how you found caregiving in general?

**Prompts:**

* Can you tell me what aspects of caregiving you found satisfying?
* Can you tell me what aspects of caregiving you found difficult?

If yes –

* How were you included?
* Can you tell me about how you have, or have not been included, as a caregiver, in decisions about your relative/spouse/friend – including the last stage of life?

If yes –

* How were you included? - For example can you describe how services have worked in partnership with you?
* What could have been done better?

If no –

* How could you have been more included?
* What do you feel prevented this?

**Experience of Services**

Can you tell me about new or additional services that you were offered, as a caregiver, once the diagnosis of palliative illness was made?

**Prompts:**

* What professionals were involved?
* Can you tell me about any support you received from learning disability services?
* Can you tell me about any support you received from palliative care services?
* What information and support was most beneficial?
* Is there anything that you felt did not work well?
* Was there anything missing from the services you received?
* Do you have any more thoughts on information that would improve support for caregivers of people with learning disabilities who require palliative care?
* Are there any other points that you feel are important to raise or any other comments that you would like to make?
* If a programme to provide information and support for family caregivers of people with learning disabilities at end of life were to be developed how do you think this could best be delivered so that family carers could have access to it?
* Are there any other comments that you would like to make about information and support for family caregivers of people with learning disabilities?

**Thank you for agreeing to take part in this interview and for giving your views and time. It is much appreciated.**