**Appendix 1** – focus group schedule HSC professionals

**Topic Guide for Focus Groups with Health and Social Care Professionals**

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

* What does the term palliative and end of life care mean to you?
* How do you feel family caregiver support fits into palliative care?
* Can you tell me about how you support a family caregiver of someone with a learning disability who has required palliative care?
* In your experience of supporting family caregivers can you describe any formal carer’s assessments?
* In your experience of supporting family caregivers can you describe what kind of information they needed?
* In your experience of supporting family caregivers can you describe any difficulties?
* What information do you feel should be provided to a family caregiver of someone with a learning disability following their loved one’s palliative diagnosis?
* Can you explain why this information in particular?
* Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to the education on either the disease the family member has, medication, death and dying and basic nursing care?
* Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to financial entitlements and benefits?
* Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to practical support such as: respite, sitting services, nursing care assistance such as homecare services?
* Are you aware of any resources or information that you could access or signpost to family caregivers of someone with a learning disability at end of life in relation to psychosocial support such as counselling, spiritual/religious support, support groups and websites?
* What helped, or would help your team in supporting someone with a learning disability who required palliative care, and their family caregiver?
* Can you tell me how family caregivers are involved in the decision making process, if at all?
* What informational provision is there to enable collaborative decision making with services if any?
* How much have you found that partnership working between family caregivers of people with learning disabilities at end of life and services takes place? Can you give examples of where this partnership has taken place?
* What do you think would help promote partnership working between family caregivers and services?
* What has been your overall experience of working with family caregivers?
* Are there any other comments that anyone would like to make?
* If a programme to provide information and support for family carers 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 all for agreeing to take part in this focus group and for giving your views and time. It is much appreciated**.