The Diversity Toolkit

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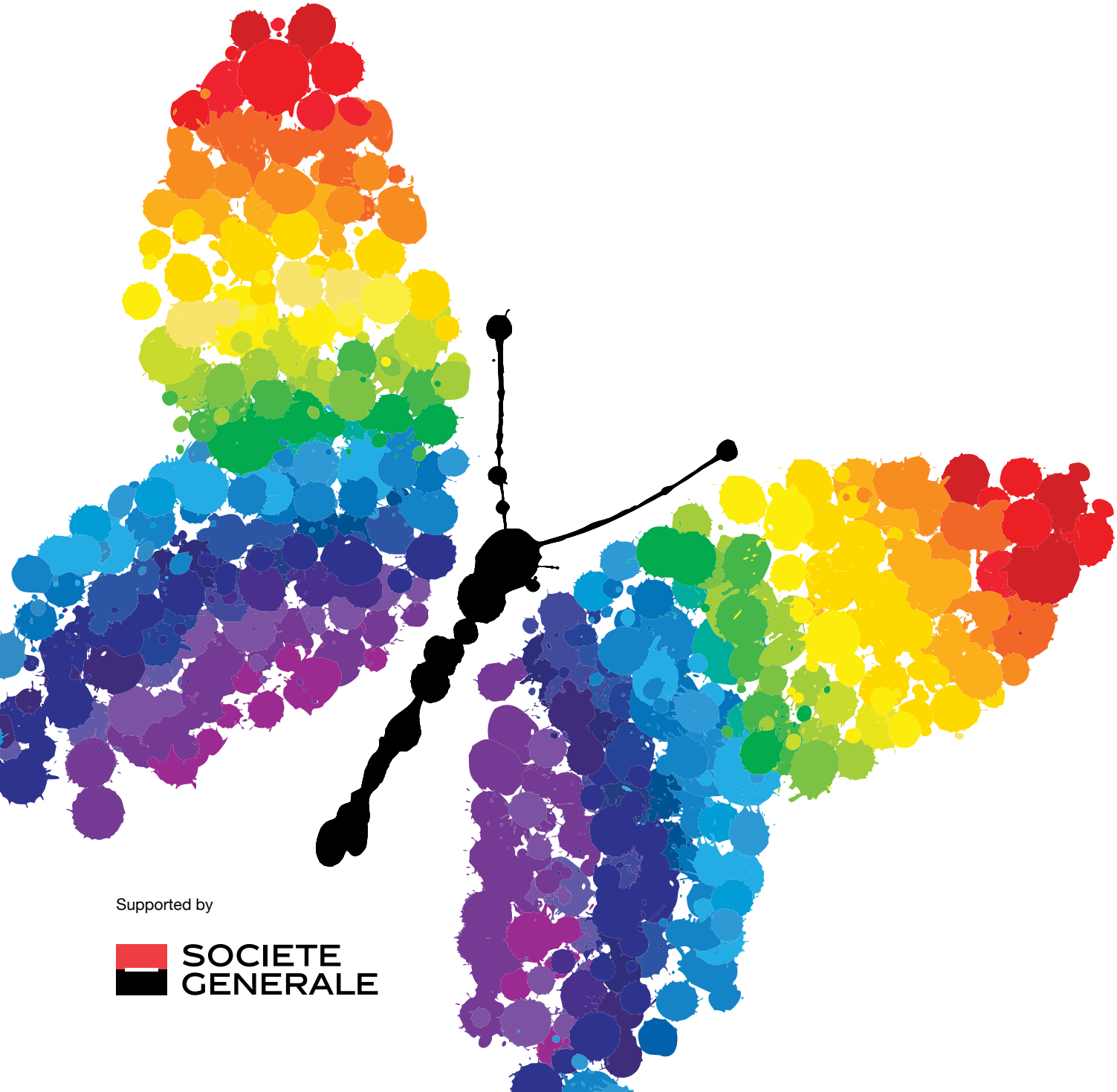
Children's Hospices UK



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1.1 Foreword

This toolkit has been developed to help children's hospice services to address the challenges and barriers faced in delivering services to children, young people and families from diverse communities. Although we have designed it for the use of our member children's hospice services, we hope that many other organisations will benefit from this resource.

Children's hospice services are committed to equality of opportunity and ensuring that the needs of children, young people and families in diverse communities are met. This toolkit is intended to assist in them in achieving this through:

- Enabling a shared understanding of what diversity means
- Identifying the legislative requirements
- Showcasing best practice and barriers to achieving this
- Highlighting and addressing organisational challenges
- Providing a framework for planning and implementing service improvements as needed.

The toolkit may highlight the need for the introduction of new procedures. Or it might help identify basic national legislation that some organisations have yet to address. Diversity and inclusion practice needs to be integrated into the strategy of all organisations thereby ensuring that it permeates at every level. For this to be achieved Board, the Chief Executive and the senior management team must champion its importance. Without this leadership and commitment very little will change.

I hope that you find this document a useful tool to supplement your ongoing endeavours to ensure that your services are inclusive to all children, young people and families in your area.

Barbara Gelb
Chief Executive, Children's Hospices UK

1.2 Acknowledgements

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With encouragement and support from Members of the Children's Hospices UK Education and Training Reference Group and representatives from other children's hospices serving on the Children's Hospices UK Diversity Reference Group.

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1.3 Background and Key Issues

Diverse Britain

Modern Britain is a very diverse society. People of many different nationalities, ethnic groups, cultures, religious or non faith backgrounds, and of different ages, gender, impairment, household type, sexual orientation and transgender status now live in Britain and contribute to making it a diverse society.

These diverse groups/communities with particular needs include gay and lesbian, gypsies and travellers, disabled people and those with learning disabilities, single parents, women and those with HIV as well as those communities that may be 'hidden' and scattered due to their low numbers or inaccessibility to services.

The population of this country is set to diversify further with the growth of the European Union and the intermarrying of different cultures, as well as the continued rise in asylum seekers and refugees and other immigrants coming to this country. This means that areas with a low incidence of BME groups in the population may rise over the next decade. Changes in the make-up of the population, the effects of migration, economic and social change, and changes in the concept of personal freedom, mean that what is perceived as the 'traditional British Citizen' is changing.

All children's hospices therefore need to provide a service that is more accessible to families from a wider range of cultures, backgrounds and circumstances.

The National Picture

The developing policy landscape has been identifying the need for all hospice/health services to develop appropriate mechanisms to provide quality and culturally appropriate services to a range of diverse communities.

The Health Select Committee Palliative Care Inquiry Report (2004) identified that there is a lower utilisation of palliative care services by BME users for reasons such as: the service being culturally

insensitive; a perception that the service is only provided for white, middle class patients; and the fact that the service grew out of a Christian charitable movement which is not perceived to be receptive to other faiths and cultures. Although this report was based on adult services, it was important to see whether a similar situation had either already been reported in regard to children's hospice services or if not, whether this was the case and if so what factors might be operating to explain this. As with adult services, reports indicated that children's hospices mostly attracted white, mainly British families.

The Korea Declaration from the Second Global Summit of National Hospice and Palliative Care in 2005 recognised that palliative care is a core healthcare service, and access to it should be considered as a human right. It stipulates the need to provide equity of care 'irrespective of age, race, gender, sexual preference, ethnicity, faith, social status, national origin and the ability to pay for service'.

The End of Life Care Strategy (DoH, July 2008) identifies the need for a step change in improving access to high-quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socio-economic deprivation.

The Race Relations Amendment Act 2000 in this country already makes it unlawful to discriminate against someone on grounds of colour, race, nationality or ethnic origin and means that voluntary organisations, such as hospices, have to comply with this requirement in providing services and recruiting staff.

The National Service Framework for Children (2004), Standard 8, builds on the five key outcomes laid down in *Every Child Matters (2004)* and the *Children's Act (2004)*, emphasising the importance of children's palliative care, including children's hospice services, being available to all young people who need them. It demands that PCTs, NHS Trusts and local authorities are required to ensure that their provision takes account of the young person's and their family's physical, emotional, cultural and practical needs.

Finally, Better Care, Better Lives 2008 also sets out how every child and young person with a life-limiting or life-threatening condition must have equitable access to high-quality, family-centred, sustainable care and support, with services provided in a setting of choice, according to the child and family's wishes.

1.4 How the Diversity Toolkit Works

1. What is The Diversity Toolkit?

This toolkit has been developed to help make real changes in the strategies, policies and practices to enable children's hospices to meet the needs of diverse communities. It provides a way to assess the current needs of diverse communities; identify gaps in your services, policies and practice; and make suggestions of how to fill these gaps. Any children's hospice, whose work needs to reach out to meet all local needs, should use this toolkit to identify, assess and develop its services appropriately. The objective has been to produce a document that is written in Plain English and that is set out in an 'easy to follow' format. It is designed as an attractive, informative but easy to navigate resource which is suitable for improving access to children's hospice services by diverse groups.

This toolkit is the first of its kind that will provide resources in relation to working with children, young people and families from diverse groups in accessing children's hospice services

2. How will it help you?

The toolkit aims to help you by:

- enhancing your existing equality and diversity assessments and raising your awareness of the issues in relation to diversity and needs in relation to policy and service delivery

- embedding the principle of diversity throughout your service planning and influencing strategic planning at all levels of your organisation

- helping you to develop and improve a range of services to meet the needs and aspirations of your local communities

- being a vehicle that helps you to develop 'good practice'

- encouraging partnerships between community groups and hospices to develop culturally appropriate services

- offering you assistance to meet a variety of legislative requirements

- giving families and children a way to influence how services are devised, directed and delivered

- enabling you to assess current performance; to identify and challenge the barriers preventing progress; and to provide advice and guidance on how to overcome such problems

- improving the strategies and policies of your organisation/team in meeting the demands of diversity

- enhancing existing monitoring and data collection mechanisms to highlight the particular needs of different communities.

The purpose of the tool is to help encourage and promote positive work within your organisation and enable you to work with diverse communities. It is important to recognise that:

- it is not a simple, quantifiable 'tick-box' assessment

- you will not achieve a score at the end of the tool

- this is not a test to be passed or failed.

3. How to use the Diversity Toolkit

The toolkit is divided into six separate modules. The tool has been designed in a flexible format so you can simply choose the modules that apply to your work, team/role and hospice needs or complete all the modules. You can also complete the modules in any order, although they have been presented within a framework of assessing, planning, delivering and monitoring services. You can also add questions to any module as you assess and develop services in your area. Using this tool will require an involved process by various staff/teams, and an appropriate allocation of time will need to be set aside for this.

When starting to use the toolkit it is important to ensure you:

- identify a person/persons in the Senior Management Team who can lead this process

- identify the necessary participants to ensure a range of

organisational roles and skills are inputting into the evaluation process - do aim to get as wide a representation as possible and include senior management, operational staff, trustees and service users

- allocate adequate time to complete the modules; it is anticipated that each module will take approximately one to two hours to compete thoroughly

- identify and organise participants into groups to complete the modules, as group discussion of individual perspectives is key to successfully completing the toolkit; this should enhance both the quality of discussion and your eventual assessment

- identify mechanisms by which the Actions will be monitored. This could be by setting up a small working group to coordinate and closely monitor timescales and implementation of actions by various teams.

At the end of the toolkit, there are appendices that give you the answers to our quiz questions, further resources if you want to find out more about any aspect of equality and diversity, and contacts if you want to talk to someone or obtain advice. They also provide guidance as Appendix 5 on structuring an Implementation Programme.

To generate thinking, we have included various examples of existing or past work by different organisations, considered as good practice, which has occurred around a particular theme. This will encourage you to consider how you might address your own issues and develop appropriate responses.

The Modules are as follows:

Module 1: Equality and Diversity Monitoring and Data Collection

Module 2: Collaboration and Community Links

Module 3: Service Planning and Access

Module 4: Listening to Children, Young People and Families

Module 5: Monitoring

Module 6: Employment Practice, Policies and Legislation

Module 1
Equality and Diversity Monitoring and Data Collection

This directs you to consider how the promotion of equality and human rights is a task for everyone in society. Service providers have specific responsibilities to their staff, service users and those under their care. The collection of robust data to monitor Equality and Diversity trends within the organisation is critical. Equality and Diversity monitoring encompasses sex, race, disability, gender, sexual orientation, and religion or belief. This is an important tool in improving fair access to service, and this module requires you to carefully consider how you collect data to fulfil these requirements.

Module 2
Collaboration and Community Links

This module aims to raise questions about what you know about your local area and how links can be formed with various organisations to work collaboratively. It will give you ideas of how you can better engage diverse groups and involve these groups, and their advocates, in improving access and service planning. It will help you identify how to make community links with these communities and advertise services. It will also help you identify robust consultation mechanisms to ensure that services are developed in response to need.

Module 3
Service Planning and Access

This module will help you consider how your organisation needs to plan current and future services carefully so that they are appropriate to the needs of all the communities in your local area. Well developed services enable a diverse range of communities to access your hospice, as well as equipping you to respond to changing diversity and needs in the area. This module enables you to evaluate the development of your services and identify barriers that prevent some families from using these. It enables you to ensure that excluded/under-represented service users are actively targeted in the planning, production, delivery and promotion of products and services.

Module 4
Listening to Children, Young People and Families

This module looks at ways in which hospice staff and services can respond to the support needs of families, young people and children from diverse backgrounds. It provides resources that enable the formulation of adequate responses in making families feel welcome and included. It enables you to develop good communication and feedback mechanisms with a diverse range of families that improve their involvement in your service planning and delivery.

Module 5
Monitoring

This module directs you to consider the monitoring and review mechanisms you have in place. It aims to ensure the intelligent collection of monitoring data to enable you to identify gaps and weaknesses in service delivery and employment practices. It shows you what to monitor in conducting self assessments when promoting equalities and diversity across the organisation and its services.

Module 6
Employment Practice, Policies and Legislation

This module aims to build an inclusive organisational culture, characterised by good relations between people – staff and service users – from diverse groups and cultures, through raising an awareness and understanding of some fundamental standards that should be present in all employment systems, policies and practices – if they are to conform to employment, equality and diversity legislation.

To start:

Each module consists of a range of questions relating to work with diverse communities. These questions are presented in either a 'tick all that apply', a 'yes and no', or a 'partly met' format. Each question has been given a priority rating (explained below in 'Prioritising Action'). For each of these questions you are asked to do two things:

1. Present either evidence or an explanation relating to your answer(s) to the questions.

2. Note your strategy/intended action for improving on your progress.

   – All questions are accompanied by useful points and resources to consider around the theme of the question, in order to guide your assessment and proposed action. Further resources to help you understand an issue are provided in the 'Resources' section of the Toolkit. Use the 'Good Practice' examples to help you assess your answers and provide information to plan ahead.

   – It is important not to worry about the quality of the answer you give, as what is important is that you make an attempt to answer.

At the end of this process, on the 'Action Plan', note:

- what actions need to be taken
- what resources are needed
- timescales involved
- key persons for leading on these activities.

After this:

- distribute the 'Action Plan' to those key individuals involved in its implementation
- arrange systems to monitor and review the progress of the action taken

Prioritising Action

It is possible that the assessment will highlight a number of actions needed. Each question of the tool is colour coded using the traffic light system of red, amber and green. These codes indicate level of priority to guide your action plans. The priority level will change, depending upon the situation of your particular organisation, ie if

you find you are already fulfilling many of the high priority areas then the moderate priority areas should increase in their level of importance.

The codes are as follows:

– immediate priority requiring immediate action

– moderate priority requiring action over the medium term

– long-term priority requiring action over the longer term.

You may find it helpful, if you find you have a number of areas of 'immediate' priority, to prioritise those that are achievable in the short term.

Long-term priority does not mean doing nothing. It is vital you think about the building blocks that need to be in place to bring about long-term change.

Some teams and organisations may not have the capacity to react to these guidelines and suggestions as others will. The important point, however, is that acknowledging something is an issue and formulating a strategy to deal with it is better than not doing anything at all.

Stages of Implementation:

Identify a person/persons in the Senior Management Team who can lead this process and identify the necessary participants to ensure a range of organisational roles and skills are inputting into the toolkit implementation process

Allocate adequate time to complete the modules. It is anticipated that each module will take approximately one to two hours to complete thoroughly.

Explain the tool and make sure that everyone understands its structure, processes and purpose

Think about the actions and progress that your organisation/team has made to date in addressing equality and diversity

As individuals, assess what stage your organisation is at, taking care to note evidence to support your assessment

Identify and organise participants into groups to complete the modules, as group discussion of individual perspectives is key to successfully completing the toolkit – this should enhance both the quality of discussion and your eventual assessment

In a group discussion, compare similarities and differences in your individual assessments as to the state of the work of your organisation/team; your differences may be more productive than consensus

Agree what action your organisation/team needs to take if improvements need to be made. Importantly, think about the barriers and assumptions that you need to challenge and about how you can build on your existing strengths

Agree when and how to re-assess your progress. Identify mechanisms by which the Actions will be monitored. This could be by setting up a small working group to coordinate and closely monitor timescales and implementation of actions by various teams.

1.5 General Equalities and Diversity Quiz

1. How many people in the UK have a disability?	A ◯ 1 in 5 B ◯ 1 in 25 C ◯ 1 in 55
2. What percentage of disabled people are born with their disability?	A ◯ 1% B ◯ 8% C ◯ 28%
3. What percentage of people with disabilities are wheelchair users?	A ◯ 50% B ◯ 15% C ◯ 5%
4. If you were in a room with 100 people how many of them would you expect to have dyslexia?	A ◯ 4 B ◯ 34 C ◯ 100
5. Most disabilities are associated with...	A ◯ motoring accidents B ◯ sports injuries C ◯ age
6. Ramadan is...	A ◯ the first day of the Chinese new year B ◯ a month of fasting for Muslims C ◯ the Hindu festival of lights

7. What percentage of the British population say they have no religion?	A ◯ 5% B ◯ 15% C ◯ 25%

8. How many mosques are there currently in the UK?	A ◯ 10 B ◯ 100 C ◯ 1,000

9. Are Rastafarians recognised as a separate racial group?	A ◯ Yes B ◯ No

10. What is the largest ethnic minority in Britain?	A ◯ Caribbean, African B ◯ Indian C ◯ Pakistani and Bangladeshis

Module One
Equality & Diversity Monitoring and Data Collection

Georgia Hazelton, Age 9, Little Bridge House Children's Hospice

Outline

The communities in which you work and serve will be made up of a multitude of diverse individuals who have differing needs.

The promotion of equality and human rights is a task for everyone in society. Service providers have specific responsibilities to their staff, service users and those under their care. The collection of robust data to monitor Equality and Diversity trends within the organisation is critical.

Equality and Diversity monitoring encompasses sex, race, disability, gender, sexual orientation, and religion or belief. This is an important tool in improving fair access to services. How you obtain this information may require some careful consideration on your part.

Good Practice

The Marie Curie Hospice in Bradford

This is a new, purpose-built and modern hospice combining specialist medical care with impressive facilities for patients.

A common referral form is used across the district, detailing where the referral is made to, the disease state of the patient, current problems and what palliative care is needed. Assessment is usually provided by the community palliative care team for home care or by the hospital 'pall-care team' /children's GPs in hospitals. The assessment form details medical background, information needs, ethnicity, interpreting needs, social, psychological, spiritual and carer needs. A note is made of preferred place of death. A management plan is drawn up. There has been a record of every patient since 1994. The data gathering and recording system for statistics on specialist palliative care is now part of the patient record system called System One. This is a district-wide tool that has proved very effective.

Source: Big Lottery Cancer Evaluation Report 2006

1.1 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you monitor both the ethnic and faith profile of your clients?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Ethnic monitoring enables the organisation to undertake community profiling in order to target the services to people/communities who are under-represented.
- ✓ Allows some insight into the ethnic profile of your client base, and highlights both large and small communities.
- ✓ Use Census categories (found at http://83.137.212.42/sitearchive/cre/gdpract/em_cat_ew.html) as a base. Add categories such as refugees & asylum seekers and Romany, Gypsy and Irish Traveller communities.
- ✓ Ethnic monitoring can show whether your organisation is offering equality of opportunity to all ethnic communities.
- ✓ Categories of ethnicity are insufficient on their own to cater for a child and their family's cultural care needs in a setting such as a children's hospice, as the meanings of ethnicity, culture and faith in individual lives can vary a lot.
- ✓ It may be more useful to record information about the patient's religion, language, culture and ethnic group.
- ✓ A lack of accurate local data about children with disabilities from diverse groups will cause them to miss out on vital initial treatments and support services offered by you.

1.2 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you monitor the spoken and written language of your clients?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Do not forget language usage can be very diverse, with some people speaking three to four languages excluding English.
- ✓ To be inclusive services, information and advice need to be flexible and ready to communicate in a range of community languages.
- ✓ Remember that some people of all ages and diverse ethnic groups are unable to read or write in any language, including their mother tongue.

1.3 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you monitor the age profile of your clients?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ The needs of young children will be different from the needs of older children and of those approaching adulthood.

1.4 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you collect comprehensive and up-to-date demographic and needs related data on communities and other diverse groups in your locality?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Effective and appropriate organisational strategies are built upon robust evidence which comes from a variety of sources eg census data (National Statistics Online: Focus on Ethnicity and Identity at http://www.statistics.gov.uk/focuson/ethnicity/), Local Authority Area Profiles, Department of Health, research evidence on local needs analysis and other community sources. ✓ Due to new migration patterns and the establishment of asylum 'cluster areas' the demographic profile of the BME population may be rapidly changing.		✓ Policies and strategies need to be inclusive, and should include the ethnic group with the largest numbers but also those with fewer members. ✓ The needs of individuals belonging to larger minority groups who are geographically concentrated may be different from the needs of those that are smaller and geographically dispersed. ✓ Links to where you can find this data are to be found in the **'Resources'** section of this Toolkit.	

1.5 r

Question	Response	Evidence and supporting information	Follow-up action required
Have you commissioned specific research or projects to find out more about the needs and aspirations of diverse groups in your area?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ Using 'official' data is helpful but approaches tailored to the community or communities you would like to know more about may uncover valuable findings and demonstrate hidden and unmet needs.

✓ Find out from local community organisations and the local authorities on any local area needs based research on diverse groups. Use existing community resources.

1.6 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you monitor race, disability, gender, religion or belief, sexual orientation, age profiles of your staff and volunteers?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ It will highlight the absence of representatives from diverse groups.

✓ It will enable the organisation to develop recruitment policies and strategies.

✓ Collection of this data must show the occupational levels of these groups, and this will highlight the need to ensure full representation at all occupational levels in the organisation.

1.7 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you monitor additional data such as the parental status of the family?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ To be able to respond sensitively and appropriately to the holistic needs of your clients – including their sexuality ie civil partnerships. ✓ Ensure compliance with the Care Quality Commission and Ofsted.		✓ Research demonstrates high numbers of single-parent families using children's hospices, and adequate data will inform the development of appropriate support strategies.	

1.8 a

Question	Response	Evidence and supporting information	Follow-up action required
Do you have a robust management system in place for the collection and analysis of equality and diversity data?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ In order that the data collected is fully understood it is important to have 'tools' to be able to analyse and disseminate the data (see Good Practice examples below). This includes data monitoring, production of effective performance indicators and well developed organisational strategies to address diversity.
- ✓ For example, looking at whether your hospice service reflects the population the local area is not enough. It is well known that certain diseases affect different groups disproportionately, and staff need knowledge of these health trends to plan effectively.
- ✓ This may require an increase in resources to purchase the right software, as well as technology and staff/volunteer training to fully utilise data collection to maximum benefit and analyse it to improve services.

Good Practice

A number of the BME schemes in the Big Lottery Cancer Research project conducted a needs assessment and / or scoping or mapping exercise. These were required to establish unmet needs and current levels of service provision and take-up. They were also necessary to address the views and levels of awareness around current provision, and to form links with appropriate people and organisations. More often than not, such exercises demonstrated low levels of awareness of service availability, provision and means of access and low levels of awareness of cancer and the causes of cancer amongst BME groups. A positive and possibly unexpected outcome was that this exercise often led to the development of links with various agencies, establishing a firm foundation from which projects could develop.

Source: Big Lottery Cancer Evaluation Report 2006

Good Practice:

Improving Data Collection

The NHS Centre for Equality and Human Rights (CEHR) hosted a patient equality monitoring project which:

- developed a minimum data set that is inclusive of all equality strands – race, disability, gender, religion or belief, sexual orientation and age
- facilitated the necessary technical changes to be made to the patient information systems operating across NHS Wales
- delivered training on data collection for front line staff. Pilots have been undertaken before mandating the service to collect the data in 2009.

It is anticipated that this data will be fundamentally important to the assessment of policy impact on different groups. A key challenge for organisations will be to ensure that these data are analysed and used to inform service design and delivery. View patient monitoring at: http://www.wales.nhs.uk/sites3/page.cfm?orgid=256&pid=12616

Source: Equality and Human Rights Commission: Making Practice Happen 2009

Good Practice

Disclosure of personal and sensitive information was raised as an issue in some cases. There were a number of BME beneficiaries who did not want other members of their community, or even their close family, to know of their illness or circumstances. There were some fears about the possible repercussions of disclosure, for example rejection or exclusion, particularly within 'closed' communities. This could also extend to fear of the project worker or others involved within a scheme disclosing personal information, particularly if they were from the same community.

Source: Big Lottery Cancer Evaluation Report 2006

Action Plan Worksheet For Modules

r – Immediate priority a – Moderate priority g – Long-term priority

Priority & Action Required	Resources Required	Achievement Indicators	Timescales	Staff Lead

Module Two
Collaboration and Community Links

Olivia Endeley-Brown, Age 8, Shooting Star House Children's Hospice

Outline:

This module aims to raise questions about what you know about the local area and how links could be forged with a range of local services, agencies and agendas in working collaboratively to improve your services.

It will give you ideas of how you can better engage with diverse groups/communities, and involve these groups and their advocates in improving access and service planning. It will help you identify how to make links with these communities and advertise services. It will also help you identify robust consultation mechanisms to ensure that services are developed in response to identified need.

Good Practice

Harlow (Macmillan) Cancer Information and Support Service

This three-year statutory-led scheme was designed to overcome previously identified gaps in provision within the Harlow PCT area, which has a high-density BME population coupled with high levels of social disadvantage and deprivation, and low levels of literacy. The scheme started slowly and suffered some early staffing problems. However, the commitment of both the steering group and project workers enabled services to develop and become embedded within the mainstream. The two (white, female) project workers both had a nursing background and considerable experience in the cancer field, but little previous experience of working with BME communities.

The scheme has been successful in its outreach work, raising levels of awareness of cancer and other health-related issues amongst specific ethnic groups – including Hindu, Muslim and Chinese communities. Access to the communities proved very time-consuming and although strong links have now been forged, considerable effort has been required to maintain them.

"[community meetings] take a...long time, you're talking about months to set up, because it's really difficult to access the people themselves...you have to be really, really determined…I found just having a friendly approach, being open, saying you don't know things and asking them to inform you...it's been a really good approach." (Stakeholder)

Services include: a telephone help-line for advice and sign-posting to (other) services; information resource centre and website; home visits and carer support by volunteers (eg transport, shopping, gardening, pet care and befriending). Clients may self-refer or be referred from other (mainly statutory) services, such as district nurses, who have valued the additional services the scheme has to offer. Clients' needs are assessed by a project worker and matched with a volunteer from the bank as appropriate.

Source: CancerBACUP 2004

2.1 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you have regular access to consultations with the communities served in order to understand their needs?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Religious and cultural norms may mean that some patterns of service delivery are unacceptable, and there is need to recognise the diversity of need between specific communities and design services accordingly.
- ✓ Is there a forum in place where diverse groups can express their needs and views on a regular basis?
- ✓ Link into consultations being carried out by local agencies to save you time and resources and prevent duplication of work. For example voluntary organisations, the PCT etc.
- ✓ Remember to also consult with diverse groups who do not appear to use your services.
- ✓ You may consider setting up a Diversity Advisory Group with representatives from relevant statutory, voluntary and community agencies to inform the organisation's work.
- ✓ It is good practice to link with other services and voluntary organisations in the area in order to both identify and fill gaps in service provision by working collaboratively.
- ✓ Find ways of sustaining these links. Ensure that it is a two-way process, with information going out to them on palliative/long-term care and information coming in to help with service planning. It is essential to keep the confidence of the communities.

2.2 r

Question	Response	Evidence and supporting information	Follow-up action required
Are these consultations inclusive?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ It is critical to ensure that consultations can take place directly with children where possible, as well as with the wider family.
- ✓ Are these consultations inclusive in terms of race, disability, gender, religion or belief, sexual orientation and age?
- ✓ Ensure that you consult with men and women equally where possible, as they may have different views/perspectives (in BME some communities there are particularly strong differences in perspectives and needs).
- ✓ Do consultation processes take into account different cultural needs (for example, women-only meetings)?
- ✓ Are you actively encouraging diverse groups to speak for themselves as well as through advocates?
- ✓ Do consultations ensure that access/participation issues for all disabled people are addressed – ie physical accessibility, financial support, hearing, and appropriate signs?

2.3 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Are you providing feedback to diverse groups on how consultation responses are translated into service delivery?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ By providing service users with whom you consulted with feedback and information on how their input into service development has been used, you will help to ensure that all diverse groups and their advocates remain part of any change.		✓ It will foster trust for future consultations and will help to create supportive communities who will be advocates for any new service developments.	

2.4 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you work together with translators and interpreters so that diverse groups can express their needs and aspirations in their preferred language?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Remember – when thinking about service provision for diverse groups, language and communication are fundamental challenges. ✓ Diverse groups will often not speak fluent English and prefer the use of an interpreter. It is important to note certain religious conventions inhibit gender association, eg Muslim women associating with males.		✓ It is important to recognise choice of the client in who interprets/ translates for them, ie family member/friends – these need to be balanced against the requirements of the communication and level of service planning. ✓ It is critical that interpreters are trained appropriately to give an accurate representation of the views of the individual and to foster trusting and confidential relationships so that they can advise clients fully.	

Good Practice

Case study: East Berkshire Palliative Care Team, Slough

This is a five-year project looking at equity of access and uptake of palliative care services in East Berkshire. (NOF funded with match funding from Macmillan). The Macmillan team is based in Slough, which has a predominantly Asian community. At the beginning of the project, only 2-3% of referrals to the Macmillan team were Asian.

The project has seen the development of the role of an Asian link worker who provides support to patients which extends well beyond their palliative care needs. The post holder works alongside the Clinical Nurse Specialist or sometimes manages cases herself, calling in nurses and other professionals as and when required. The post developed out of recognition that people needed more than just an interpreter – they needed somebody who understood the systems, and who could explain the systems to them and work alongside them in accessing appropriate health and social services.

"She's got involved with things like helping with housing benefit, helping getting a relative over from India because they were going to care for the patient, negotiating with the local MP to get visas for relatives to come over… So it's much bigger than specialist palliative care. Patients would be referred to us with a palliative care need but as with any population, their palliative care need is only part of their life and for some minority groups there are other issues which take precedent."

The project has also looked at where the barriers to referral occur – identifying many of the possible barriers outlined in phase one of this research. Among the most interesting findings was that 'palliative' does not directly translate into many Asian languages, making the concept particularly hard to understand.

"One of the key learnings has been that for a lot of minority populations, particularly the Asian population, there is a big issue about the importance of hope. Treatment and hospitals are seen as a place of hope. Therefore to even bring up the suggestion of palliative care and a hospice is quite a difficult concept… How to phrase it so you can still see there's hope but hope is something different. Not hope for cure…"

Knowledge and awareness of palliative care services were low, and even when patients were aware that hospice care was an option, they often assumed that it was a service you had to pay for.

"The whole concept of a hospice. Most patients were not really aware of it at all. If they did know anything, there was this assumption that they would have to pay."

The team has shown a group of multi-faith leaders around the hospice both to get their opinion about how they could make the service more equitable, but also to inform them about the service so that they could pass the information on to their communities.

"They made very good suggestions. Like, in your multi-faith room we could give you a prayer mat. They were quite willing to give things to the hospice to make it more culturally acceptable. And just little tips, like if you had a welcome sign in different languages, that immediately makes people think they are welcome. That was useful."

The project has had a small impact on referrals – now about 6% of referrals to the Macmillan team are Asian. There was recognition that the work needed to continue.

"It's one of those things you have to keep on with. You have to be proactive all the time, I think. It's not something you can do a big splurge and think, right, that's it, we've cracked that one. It's very much an on-going dialogue. It keeps reinforcing the message about what's available, how you access it, what you will or won't have to pay for. Because I think the key thing is that most people do not understand what services are available."

Source: Report by Social Research Network 2006

2.5 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
If you have identified needs for services that are not currently being provided, do you pass this information on to the local PCT as part of their Commissioning processes?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ It is important to share information on these to input into local Commissioning and Care Planning Strategies to ensure appropriate allocation of resources and development of policy to implement effective services.			

2.6 r

Question	Response	Evidence and supporting information	Follow-up action required
Does your organisation share good practice with local authorities, Primary Care Trusts, other organisations and providers with respect to their work with children from diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Some organisations may have existing practice or new and innovative ideas and input into how needs and aspirations of diverse groups can be met.
- ✓ To make your organisation sustainable, it is important to set up systems for recording the 'intellectual capital' of good practice and make it available internally as well as externally.
- ✓ Sharing of good practice can result in better services for clients, increasing resources and strengthening community links.
- ✓ It is good practice to develop and maintain a local and national directory of resources.

2.7 a

Question	Response	Evidence and supporting information	Follow-up action required
Has your organisation formed any partnerships with organisations and other specialist agencies that cater for the needs of specific diverse communities?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Specialist agencies will have detailed insight into the needs and aspirations of their particular client group.
- ✓ Linking with these agencies may help your organisation enormously by informing and helping direct your plan to improve service reach and service availability for these communities.

- ✓ Faith-based and work-based organisations often provided good access points to the target groups. Festivals and organised events also provided access to the local diverse groups. Face-to-face communication was frequently reported as the most appropriate means of communication, but, this requires considerable time and effort.

Good Practice

Brent and Harrow children's palliative care scheme.

The aim of this home-based scheme is to develop and improve existing services in the locality for children with life-limiting or life-threatening conditions needing home-based palliative care.

The scheme represents a partnership between two Primary Care Trusts and an acute hospital trust. The scheme is located within an urban area of high levels of deprivation and almost 50% minority ethnic population. The caseload remains relatively small, with 18 families across the two districts.

Many of the families are immigrants, and translators are required to assist communication. Visits therefore require careful planning and longer than they would with English-speaking families. Translators are quite widely available within the GP practices and PCTs across London, covering many of the major languages of the BME groups living there. However, some communication difficulties have been reported in relation to certain dialects.

This scheme has worked successfully in partnership with various local agencies. These include Macmillan Cancer Relief, which has provided continuation funding for the next three years. After this the PCT has agreed to support the scheme.

Source: CancerBACUP 2004

Good Practice

St Gemma's, Leeds

St. Gemma's Hospice has operated as an independent charity from its foundation in 1978. Its development has been guided by the needs of patients.

In 1999/2000 proposals were submitted by St Gemma's and Sue Ryder Wheatfields to the Health Action Zone for funding of a Joint Leeds Hospices Ethnic Minority Project. This was active from 2001 to 2003. It was set up to address the perceived inequalities that BME groups experience within existing hospice services.

A project manager was funded for two years and four community workers were appointed – representing the Bangladeshi, Pakistani, Indian, African Caribbean/Chinese communities – to liaise with the hospices. Specific activities have included: a series of information evenings such as Asian, Turkish, Polish, Chinese so that people could come and see the building; links with local priests and rabbis and a key contact with the Sikh community; translation of information materials on hospice services into six languages (Urdu, Bengali, Hindi, Gujarati, Punjabi and Chinese); and dissemination to a database of people including GP practices, clinics, libraries and community groups. Feedback has been positive. A handbook on all the different religions and beliefs is available on each floor and is referred to frequently.

Source: Report by Social Research Network 2006

2.8 a

Question	Response	Evidence and supporting information	Follow-up action required
Do you involve diverse groups in your fundraising activities?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ Using fundraising events can be an effective tool to break into diverse communities.

✓ Fundraising provides information on your services.

✓ By encouraging diverse groups to invest in your work, you can foster sustainable and trusting collaborative community relationships.

2.9 r

Question	Response	Evidence and supporting information	Follow-up action required
Is there a method for signposting organisations and individuals from diverse communities to your services?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Are your services advertised and easily accessible in other services' directories?
- ✓ Remember it is important to make your services known via the local BME media and local community groups that represent diverse communities, as this will ensure maximum reach for access (see Module Three).
- ✓ Use the media imaginatively to get messages out to target groups. For example, work with communities to provide radio programmes on cancer to be broadcast on stations that are listened to by BME audiences. Use different combinations of cancer information specialists, medical consultants (some from within the target groups) and if necessary interpreters, depending on the needs of the community you are trying to reach. In some areas, phone-in question-and-answer sessions have been especially appreciated, and several regional radio stations have taken the opportunity to host cancer awareness talks.

Good Practice

UMEED, Nottingham

This voluntary sector grant scheme was located in an inner city area with high levels of ethnic minority communities, particularly of Pakistani origin (Mirpuri) and followers of the Muslim faith. The parent, an Asian women's organisation, has been established for over 20 years and had been looking to diversify into the health arena.

The BIG grant provided the opportunity to realise this ambition. The scheme was designed to: reduce anxiety and fears through information and education; help cancer sufferers and their families and carers through the development of self-help; set up appropriate referral mechanisms to link the project with mainstream provision; and support research in partnership with the local hospital trusts, to examine reasons for the low uptake of mainstream cancer services by people from ethnic minorities. The target group was identified as 75% patients and 25% carers, who would be expected to come from Indian (25%), Pakistani (50%) and Bangladeshi (25%) communities.

Although the parent body is specifically a women's organisation and the project workers were all young females of South Asian origin, some generic work was carried out through radio programmes and working with families affected by cancer.

In order to raise cancer awareness, training sessions were carried out with local women's groups; use of a local radio station for cancer awareness programmes provided access to a wide (but unquantifiable) audience. A resource unit was created, stocked with cancer information in a variety of written and audio formats in a variety of languages, and from a variety of mainly charitable sources such as CancerBACUP and the AFIYA trust.

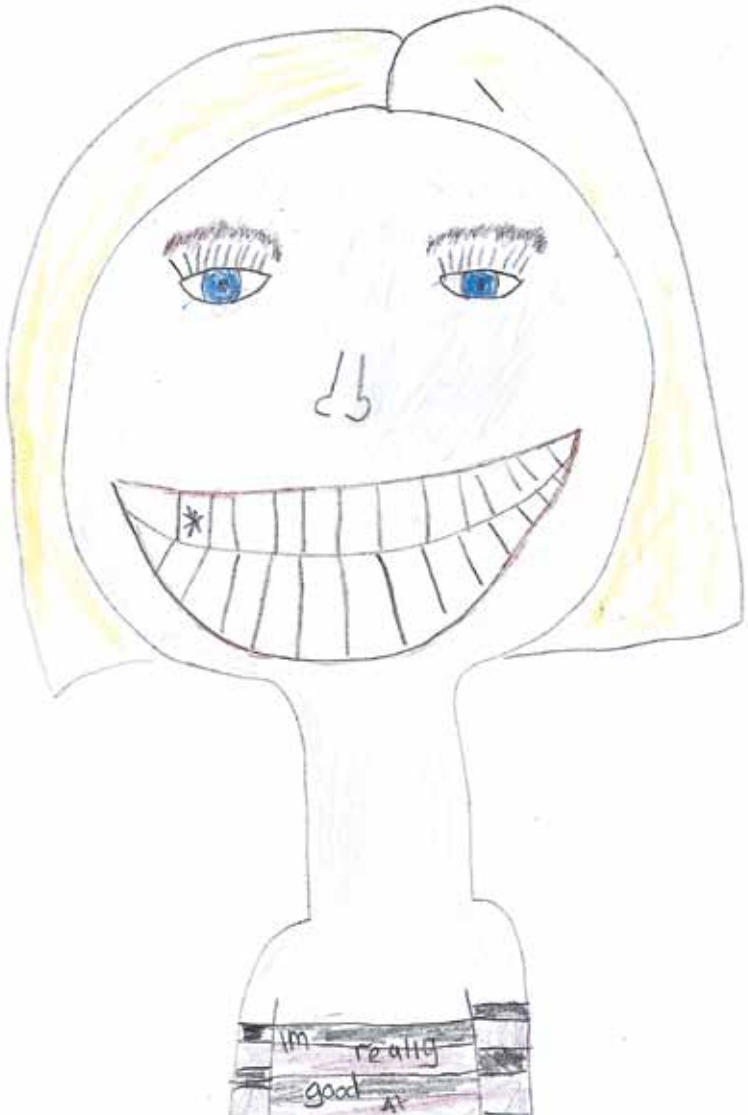
Source: Big Lottery Cancer Evaluation Report 2006

Action Plan Worksheet For Modules

r – Immediate priority a – Moderate priority g – Long-term priority

Priority & Action Required	Resources Required	Achievement Indicators	Timescales	Staff Lead

Module Three
Service Planning and Access



Outline

Your organisation needs to plan current and future services carefully, so that they are appropriate to the needs of all the communities in your local area. Well developed services enable a diverse range of communities to access your hospice, as well as equipping you to respond to changing diversity and needs in the area. This module enables you to evaluate the development of your services and identify barriers that prevent some families from using these. It enables you to ensure that excluded/under-represented service users are actively included in the planning, production, delivery and promotion of products and services.

Shannon Taylor, Age 8, Rachel House Children's Hospice

Good Practice

A number of children's hospices have employed cultural workers/liaison officers. This role provides a community-based service offering psychosocial support, advocacy and consultancy, and training for existing staff.

Acorns Children's Hospice, Birmingham

The benefits of Cultural Liaison workers being employed by Acorns Children's Hospices are:

- increased links with BME communities
- increased referrals from BME communities
- organisations becoming more culturally competent in generic practice
- organisations embracing wide issues of diversity and inclusion for all.

Rainbows Children's Hospice, Loughborough

The Rainbows Children's Hospice experience has:

- ensured that Diversity has become an integral part of the organisation through the development of policies and targeted mandatory training
- encouraged parents of children with life-limiting conditions to find out more about the service and receive support
- increased the availability of resources and artefacts available within the Hospice
- raised awareness of cultural issues amongst all staff within the hospice
- became a resource for all staff and families
- identified a specific need to support isolated Asian mothers whose culture has made wider social networking difficult, and subsequently established an Asian Mothers' Lunchtime Group.

3.1 a			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you have a good understanding and plan of the needs of diverse groups and how these might change over the coming years?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ It is important not to make assumptions on existing and emerging needs. For example, evidence has found that young disabled South Asian people have a strong desire to hold on to their culture, religion and ethnicity and little evidence of intergenerational struggle within this group.
- ✓ Understand the need for policy and practice to recognise diversity. Do not assume that western ideas about death, disability, and independence have the same meaning for different BME communities.
- ✓ Have you consulted up to date data and relevant literature that focus on diverse communities and their emerging needs?
- ✓ You need to adequately plan your service to ensure future appropriateness and sustainability.
- ✓ Ensure that services are developed that comply with current and emerging legislation.

Good Practice

The problem of transport to and from children's hospice services could be addressed by encouraging the use of volunteer drivers, possibly from the same ethnic community. Macmillan Cancer Support has designed a mobile centre for targeting diverse communities. This centre travels to areas with high diverse populations to provide screening for cancer as well as information and support (Race for Health, 2006). A similar centre travelling to areas of high diverse representation would be a good way to promote children's hospice services to families from diverse communities.

3.2 a

Question	Response	Evidence and supporting information	Follow-up action required
Do you have a communications strategy that identifies how you communicate with diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Although you may be aware of a smaller number of predominant languages spoken in your area, you may be excluding those who speak languages you are not yet aware of.
- ✓ Maintain links with a range of voluntary and community organisations in order to keep informed of the changing nature of the area.
- ✓ You may need to 'free up' some time to enable staff to actively engage with these communities.
- ✓ The word 'hospice' can be a barrier to the use of adult hospices by diverse groups. There is no translatable equivalent of the word 'hospice' in any of the Asian languages as this concept of care is primarily Western.
- ✓ Once patients have been admitted to hospice care, their fears can be allayed.
- ✓ The information leaflets for parents about hospices, as well as being in different languages and mediums such as DVDs, should cover all issues for families from different cultures. This will reassure them that their culture and religions are respected and their needs will be catered for empathetically eg 'easy read' formats and pictures.
- ✓ Make sure any promotional materials reflect diversity, eg images and voices of people from different diverse groups and background ethnic music.

3.3 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does your Mission Statement show a clear commitment to serve diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Strong value statements are integral in demonstrating that your organisation is going to do something to address inequality faced by people from diverse backgrounds. ✓ These need to be clearly visible and accessible in all your information, literature and websites – rather than present but hard to find.		✓ Use visible signs at the hospice that demonstrate a commitment to equality and diversity. These are useful tools in welcoming and fostering trust. For example, using hand symbols on posters to represent greetings in different cultures, posters celebrating diversity in different parts of the hospice.	

3.4 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you provide easily accessible information to diverse groups that enable them to understand your hospice services?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Language is a key barrier preventing some diverse groups/communities from understanding the work you do. In some languages, the term 'hospice' has no equivalent translation and it is important to find means of communication that are effective to promote understanding.
- ✓ Also remember that in your local community there may be a range of languages spoken: don't assume that one language is the norm and understood by all members of the community.
- ✓ Ensure that information and appropriate support are provided to families or children who are visually impaired or partially sighted, who may not be able to access your generic literature.
- ✓ Remember that people may not be literate in their own language and you may need to use innovative/appropriate ways of getting your information across to other diverse groups: open meetings, face to face, audio/video, TV/radio, Braille, large print.
- ✓ Translation of materials may need to be supplemented with interpretation to explain some complex service concepts. The use of illustrations must reflect the diversity of the whole community.
- ✓ Assess effectiveness of publicity materials. For example, apply a 'lowest read score' assessment and also ensure material is in Plain English.

3.5 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you improve access to your hospice by ensuring physical accessibility is appropriate for diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Is the hospice fully equipped to meet the needs of disabled families and children? For example, does it have lift access, hearing loops?
- ✓ Offering assistance with transport enables many diverse families who do not have their own transport to access the hospice location/service.
- ✓ Remember, your geographical location coupled with transport difficulties and social exclusion can make it difficult for many diverse families to access your services. You may need to develop strategies to counter this.
- ✓ The location of hospices in predominantly white, middle-class areas could also present a barrier to access for diverse families.
- ✓ Ensure tools of multi-sensory communication are available: use of Makaton, pain assessment tools, and sensory equipment. You may need to consider how Makaton works differently in different languages.
- ✓ Be aware of stigmas in some diverse communities and the barriers faced by families in publicly being seen with their disabled child.
- ✓ Think carefully about the physical environment to make it more appropriate for people of different faiths and cultures but avoid tokenistic gestures – the most important consideration is appropriate care.

3.6 a

Question	Response	Evidence and supporting information	Follow-up action required
Does your referral and assessment process enable improved access by diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Referral patterns are not the same in all communities and in some instances, self referral is less likely to happen.
- ✓ Some migrant communities are unfamiliar with community-based primary care services, and think of health and care services as mainly hospital based.
- ✓ Provide serices and information in places where people meet or use other services to raise awareness, also visiting their homes for individualised assessment and support.
- ✓ Does the referral and assessment form adequately capture relevant information on families and children's cultural and varied diverse needs arising from disability etc?
- ✓ Assessment and care plans should also include such needs as washing and dietary requirements as well as other care needs, including end-of-life care which may differ depending on the ethnic group.
- ✓ Have a system to follow up a family's reasons for terminating the use of hospice services, so that continuing barriers can be identified.
- ✓ Be aware of how some cultural concepts of 'izzat' – meaning family pride, honour or reputation – play an important role in the lives of families from some BME communities. Having a child with a life-limiting condition can affect the honour of the whole family, thus affecting the means of communication for the entire family. If a child is diagnosed with a life-limiting condition then there might be the possibility that due to 'izzat' this diagnosis will remain undisclosed and the family may choose not to seek professional advice, support or even treatment.

Good Practice

Douglas House Hospice, Oxford

Douglas House currently has one guest who uses British Sign Language and a number of guests with a hearing impairment (some of whom are hearing aid users).

At Douglas House, it is believed that support goes beyond being wheelchair accessible and culturally aware, and extends to young people with sensory impairments, plus those with varied communication methods. The occupational therapist has a huge amount of experience of supporting people with sight impairments, which led to a focus on people with hearing impairments.

Aside from practical adjustments to the building, and special equipment (such as pagers for fire alarms etc), Douglas House is concentrating on the communication issues. The aim is for all staff to attend basic British Sign Language Classes and Deaf Awareness Training. In terms of current guests and future referrals, this means that staff are able to communicate with deaf young people more effectively. As some of the main aspects of the role on the care team are socialising with, listening to and providing emotional support to guests, it is felt to be essential for staff to be trained to communicate in a variety of different ways. Douglas House uses the services of a qualified BSL/English interpreter for more in-depth medical discussions.

3.7 a

Question	Response	Evidence and supporting information	Follow-up action required
Does the hospice environment reflect the cultural and religious preferences of diverse communities?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Use resources and displays that reflect the diversity and positive examples of different cultures. For example, is the religious artefacts cupboard in a prominent place and representative of the needs of communities served?
- ✓ Display culturally diverse material like a faith calendar and cultural pictures/posters in appropriate areas to increase a sense of inclusiveness and familiarity.
- ✓ Ensure that you have appropriate DVDs, MP3 players, play stations, newspapers, toys, world music, etc – to reflect different cultural preferences.
- ✓ Provide a multi-faith room/quiet room that offers space for different faiths to use is good practice.
- ✓ Provision of adequate washing facilities that meets the needs of different cultures is good practice: this can be facilities to wash before prayer and washing the body at the time of death.
- ✓ Have certain key cultural appropriate features in bedrooms, such as: an arrow pointing to Mecca to help with prayer.
- ✓ Some families may also be concerned about services catering for their personal care needs such as the provision of appropriate washing and toileting facilities.
- ✓ Different cultures and religions' attitudes towards exposure of the naked body – even just parts of it – need to be respected, for instance when families from diverse groups use a Jacuzzi or swimming pool. They might be reluctant to use the Jacuzzi at the hospice unless the family can be in there on their own.
- ✓ The dislike of the pig by Muslims because of its supposed dirtiness is mentioned not just for dietary purposes but also more widely in their daily lives: you might not give a Muslim child a cuddly pig as a toy as that might offend the family.
- ✓ These issues obviously need top be considered when decorating and equipping the hospice environment with items such as books, toys and games – as well as when preparing, cooking and providing food.

3.8 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does your referral and assessment process enable improved access by diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Cultural needs must be included in the care plan at the time a child is booked into the hospice. This can include preferences in activities, gender care and meals.
- ✓ Cultural and religious issues may influence whether children prefer contact with staff/volunteers of their own gender.
- ✓ The timing of treatments that a child might be undertaking can also impact on a family's wishes if they clash with religious festivals such as Yom Kippur or Ramadan, or prayer times.
- ✓ Staff need to be trained adequately to respond to different cultural expectations and practices at a child's death and bereavement.
- ✓ Remember that for some communities, bathing in public areas like the swimming pool is only appropriate with adequate dress and privacy provision. Be aware of practices like the need for curtains in shower areas, alternatives to swim suits such as the wearing of Asian dress or T-shirts/sweat pants, and offering the choice of single-sex bathing where practical.
- ✓ Remember the need to provide appropriate personal care products eg hair and skin care, for children from different ethnic communities.

3.9 a			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you have arrangements in place to manage and support the health needs of gypsy and traveller children?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Modern Gypsies and Travellers, who have descended from the Roma, may still adhere to traditional customs which have a strict code that classifies outsiders or non-Roma people as soiled or unclean. This code prevents interaction with the Gadj or non-Roma people.
- ✓ In the healthcare setting, only the elder males are likely to communicate with healthcare personnel. A women is not permitted to interrupt men or to be alone with a man who is not her husband or relative.
- ✓ For the Roma, illness is not just the concern of the individual but a problem shared by the entire group or clan. When a clan member must enter a hospital, family members are expected to remain with that person day and night to watch over, protect, and perform caring and curing rituals. This cultural coming together is one of the strongest values of the Romani culture.

Cultural Practice

When a child dies, for example in a hospice, it might be the cultural requirement for the Gypsy and Roma families to visit en masse as it might not be their custom to send flowers or cards. This might be difficult for staff to understand if they have not been made aware of this possibility through cultural awareness training. A negative attitude towards many visitors has the possibility of being interpreted as racism and may lead to damaging feedback to other families.

Good Practice

Children's Hospice Weekend

A seven-year old girl with Duchenne Muscular Dystrophy achieved her dream of riding a horse. A hospice-at-home team arranged for the little girl, who is wheelchair bound, to go horse riding. Considerable assistance was required from six supporters and a risk assessment had to be carried out as part of the planning process, but the little girl's dream came true.

Children's Hospice at Home scheme

A group of seven teenage boys and young men (aged 13-22) attended a children's hospice for a weekend of fun activities. The group all have Muscular Dystrophy, which means that they are all confined to wheelchairs. They have various levels of physical disabilities. For example, several still have the ability to feed themselves, whilst others do not. Their cognitive ability, on the other hand, is comparable with their chronological age. The group acknowledged that the benefits are largely for their parents / caregivers, who can do 'normal' things while they are 'out of the way', such as clean the house, or go out for dinner together. However, the group quickly settled into playing computer games together and levels of excitement rose. Conversations ranged from the latest computer games and pop CDs to the latest upgrades of electric wheelchairs.

Source: Big Lottery Year 3 Palliative Care Evaluation Report 2006

3.10 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you have systems in place to deliver effective services for families or children with a learning disability?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ There are different types of learning disability, ranging from mild to severe. Many people with a learning disability will also have underlying health problems that sometimes go unnoticed, so it is important that health professionals are aware of what to look out for when caring for people with a learning disability.
- ✓ Listen to parents, carers and support workers, especially when someone has difficulty communicating. They can tell you which signs and behaviours indicate distress.
- ✓ Be clear on the law about capacity to consent. When people lack capacity, you are required to act in their best interests (refer to the Mental Capacity Act information in Resources - Section 3).

3.11 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you have the skills and knowledge to care for a child living with HIV?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ People with HIV say they are often made to feel different by doctors, nurses and other health workers. Whether that stigma is real or perceived to be real makes no difference. ✓ A recent report by the African HIV Policy Network suggested that HIV in BME communities is portrayed as an 'African' health problem, and thus perpetuating the stigma towards this group whilst discouraging considering HIV as a health problem for people from other ethnicities.		✓ There is growing evidence that stigma and negative attitudes impact negatively on the benefits of treatment, with a higher number of people dying if they said they felt stigmatised by health care workers.	

3.12 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you plan activities that are responsive to the preferences of diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Varied activities can be planned that meet the preferences of different communities for eg: celebrating some religious days, trips to places of community interest, world cinema etc.		✓ Be aware that for some communities, some days of the week (for eg: Fridays for Muslims, Saturday for orthodox Jews) are less suitable for community events or activities. This is important when planning the engagement of families with services as all religious and cultural groups have time they prefer not to engage with your services.	

Good Practice

Acorns Children's Hospice, Birmingham

Acorns has held four Diversity Events, the primary aim of the events was to raise awareness of the work of Acorns Children's Hospices, particularly in relation to their work with diverse communities.

Two of these events were professional workshops and two took the format of social events. The social events included food and entertainers with over 300 people attending the first event and 700 attending the second.

Offering social opportunities to celebrate festivals and events can be a fun approach to embrace diversity. This can be achieved in a number of ways:

- celebrating Diwali
- having Sari and Mendi days

- celebrating Eid
- having a St Patrick's Day party
- marking Black History Month with visiting poets and having themed activities.

Good Practice

Helen and Douglas House, Oxford

Helen and Douglas House was approached by SpecialEffect, a charity dedicated to helping young people with disabilities to enjoy computer games. For these children the majority of computer games are simply too quick or too difficult to play. SpecialEffect is working with Helen and Douglas House to provide truly accessible computer games, as well as an Eyegaze computer which allows children and young adults with good eye control to use this as a method of communication, to play games or even music. Giving children and young adults with disabilities the chance to play, learn and interact on their own terms makes an enormous difference to their self esteem, confidence, communication and enjoyment of life. For more information, see http://www.specialeffect.org.uk/pages/helen.htm.

3.13 a

Question	Response	Evidence and supporting information	Follow-up action required
Are your staff trained to support the needs of young adults who wish to engage in discussions and activities relating to any aspect of their sexuality?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ This may present challenges to staff. They need to be trained to support individuals to appropriately deliver this aspect of care.
- ✓ Be aware that in some instances the wishes of the young adult may be opposed to the wishes of the parents and their cultural/religious expectations.
- ✓ Careful consideration is needed of issues such as legality, maintaining staff dignity and personal values, and ensuring that activities do not cause offence to other guests and families.
- ✓ Concerns about disclosing sexual orientation can lead to avoiding or delaying seeking healthcare when needed. LGBT people can be reluctant to disclose their sexuality even if discrimination is only perceived rather than actually experienced.

Good Practice

Helen and Douglas House, Oxford

A young man in his early 20s with Duchennes Muscular Dystrophy expressed his desire to lose his virginity before he died. As an organisation that prides itself on listening to need and trying to add quality to shortened lives, the organisation was faced with a predicament ethically, professionally and in terms of reputation and public image. Staff tried to consult widely with other organisations and had helpful feedback from a Professor of Theology at Oxford University, Outsiders, Leonard Cheshire Homes, Treloar's College and the family of the young man with his permission.

After much internal discussion involving trustees, the Ethic Committee and the Management Committee, it was decided that the organisation would support a member of staff who currently provided outreach support to this young man to assist him in accessing and using the internet to find a surrogate worker (a sex worker for the disabled), something the young man was physically not able to do unless supported.

The outreach worker also helped to make arrangements for the visit and was available to discuss the young man's own requirements and needs as well as being available to provide support for the young man during the surrogate worker's visit and afterwards.

In addition the organisation was able to support the family of the young man, who were uncomfortable with the young man's decision and felt unable to support him themselves.

3.14 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Are you able to provide meals that meet varied cultural/ dietary needs?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Provide a choice of menus that meets not only the family's cultural preferences for their child but also the child's own preferences.
- ✓ Remember that food cooked on site to restaurant or standard recipe specifications can be very different from what different ethnic groups are familiar with at home.
- ✓ Be sensitive to times that people need to 'fast' for religious reasons or need food cooked in a particular way, eg: dietary preferences, choices for children, young people and staff, halal, vegetarian, vegan.
- ✓ Be sensitive to the need to keep cooking utensils and preparation areas separate in the kitchen for vegetarian and non-vegetarian food.
- ✓ In Muslim families, women choosing to wear a veil in front of unknown males can feel the indigenous population sees them as different. It is therefore important to ensure that families can eat on their own at the hospice if they do not like to eat at the communal table and in a mixed gender group.
- ✓ It is important to let families know that they could make use of other cooking facilities at the hospice if they wanted to make their own food.

Good Practice

Acorns Children's Hospice, Birmingham

Food features highly as part of the care and support offered when caring for children, young people and their families. Ensuring all dietary need is catered for is a priority for all hospices. Acorns Children's Hospice has more than 40% of families from South Asian communities, and a varied menu is available each day to include vegetarian or culturally dietary needs as necessary – eg halal meat provided on request.

Suggested guidance:

- separate sections should be provided for vegetarian and non-vegetarian foods in all freezers
- separate utensils for serving meat and vegetarian dishes should be provided
- separate cooking pots and pans for meat and vegetarian dishes should be provided
- halal and kosher meat should be provided as appropriate, with a variety of other food types meeting cultural preferences.

Comments from Acorns families have included:

"I am really impressed that they can cope with a vegetarian diet"

"The food is phenomenal – lovely home cooking"

"The diet offered my son is really healthy – I don't have to fill in any gaps but I generally make a bit of pudding and bring it in for everyone to share"

(Taken from Family Feedback about Routine Respite Care at Acorns, May 2008)

3.15 a			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you have good operational guidance on all aspects of providing services to diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ It is good practice to understand and assess the needs of your local communities and develop operational guidance to staff that encompasses practical detail on service planning and provision.			

Action Plan Worksheet For Modules

r – Immediate priority a – Moderate priority g – Long-term priority

Priority & Action Required	Resources Required	Achievement Indicators	Timescales	Staff Lead

Module Four

Listening to Children, Young People and Families

Judith Merry, Age 18, Helen House Children's Hospice

Outline

This module looks at ways in which hospice staff and services can respond to the support needs of families, children and young people from diverse backgrounds. It provides resources that enable the formulation of adequate responses in making families feel welcome and included. It enables you to develop good communication and feedback mechanisms with diverse families that improve their involvement in your service planning and delivery.

Good Practice

Acorns Children's Hospice

Supporting a parent with a learning disability

Jack was nine months old when he was referred to Acorns. He was described as a nine-month-old boy, born to a mum who had 'concealed' the pregnancy. His prognosis was poor, and although he did not require hospital care he was going to need significant nursing care for the duration of his life. Jack's mum, Sally, was described as being incapable of meeting his basic needs due to her learning disability. She had, however, travelled daily by bus and train to sit with him in the hospital. Jack was placed with foster carers when Acorns first became involved.

When the community team worker first met Sally, Jack's mum, she sat hunched up, avoiding all eye contact with the foster carer and the social worker, and answered the questions asked. When she was visited on her own at home, it soon became clear that she loved Jack but did not know how to care for him and wanted someone to help look after him. She was aware he may not live very long and wanted the best for him. Her oldest son, Alan, had a mild learning disability and could be aggressive towards mum. He was very heavily dependent on Sally for emotional security, and she found herself frequently torn between being there for Jack and responding to the emotional demands of Alan.

Sally would agree immediately with whatever was being proposed, but after processing the information, she would change her mind. This had been seen by some agencies as her simply being uncooperative.

Sally knew that children died at the hospice and was able to articulate her wish for Jack to receive end-of-life care at the hospice.

Much of Acorns staff intervention consisted of asking Sally what she understood of the situation and of Jack's (and Alan's) needs. Sally relied heavily on frequent visits and support over the phone.

A plan to move Jack into long-term foster care involved Sally accepting reduced contact with Jack, dropping down to letter box contact, ie two letters a year.

However, before a placement was found for Jack, his health deteriorated and he died in the hospice. The community team worker supported Sally and Alan when they visited Jack at the hospice later that night and the next day – Sally had no transport and a fear of officialdom, so the worker was able to support her in registering Jack's death.

Sally was able to give clear guidelines as to where she wanted Jack to be buried. She was also very clear about who she did and did not want to attend. She was supported to plan the funeral and to liaise with her solicitors when appropriate.

Key Messages

- Assess the body language of parents and carers who have an identified learning disability
- Allow for a period of time for reflection on agreed actions
- Empowering and validating the views of all parents/supports to engage in planning processes and to access future support.

Good Practice

Marie Curie Hospice, Bradford

The Marie Curie Hospice in Bradford is a new, purpose-built and modern hospice combining specialist medical care with impressive facilities for patients.

The hospice recruits from the Asian community, and currently has about four trained nurses of Asian origin out of 50 nursing staff (trained nurses and care assistants). The hospice also has nursing and physiotherapy students, often from ethnic minority communities.

There are two ethnic minority liaison officers in post. The officers are able to give an explanation of the palliative care team to the family, and can quickly assess the family dynamics (such as relationship between husband and wife). This really helps with the first holistic palliative assessment of needs. In addition, specific needs can be identified such as dietary needs. The officers have responsibility for translating, interpreting, explaining the services and options to families, giving advice, supporting outreach in the community, and providing support to both patients and staff. As well as care of the patient, there is advice on benefits and bereavement counselling for family and carers.

Evaluation of the appointments has found that they improved communication between professionals and patients, improved needs assessment and probably increased the use of hospice services by patients of Asian origin. Referrals to the palliative care services have doubled in the last ten years, and there has been a significant increase in non-malignant conditions such as heart failure, diabetes and renal failure.

Source: from Report by Social Research Network, 2006

4.1 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you involve children, young people and families from diverse groups in planning a range of services?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Involving communities at an early stage of service development is essential in ensuring that services are responsive to needs and sustainable in the long run.
- ✓ Experience shows that good ideas are often introduced for a limited time, without adequate evaluation or consultation with the communities being served, making them unviable in the long term.
- ✓ Consult and visit other children's hospice services that have good representation of BME families, using them for advice and ideas.
- ✓ Consult and involve people from diverse communities in planning provision of the hospice service, including religious and cultural leaders.
- ✓ Encourage community involvement in running the hospice service, such as through participation in some activities like fundraising and arts and music workshops.

4.2 a

Question	Response	Evidence and supporting information	Follow-up action required
Do you employ staff/ volunteers who are specially trained to work with children, young people and families from diverse backgrounds?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Having key workers who speak the same language or have been trained in diverse needs/understand aspects of the family's background is a positive way to introduce families to a hospice and increase confidence.
- ✓ Even speaking a few words of a familiar language to a child or the parents can ease the anxiety that any face when coming into an unfamiliar environment.
- ✓ There is also a need for any care staff to understand the meaning of non-verbal communication when caring for children and families from a diverse cultural background; being able to understand facial gestures, intonations of speech and body postures can sometimes communicate more than words.
- ✓ The impact of there being fewer care staff from diverse groups and a lack of appropriate medical and other care staff of the acceptable gender can also be an issue for families from diverse cultures (for instance, the lack of male nursing staff to care for boys from some diverse communities is likely to be problematic).

Good Practice

Rainbows Children's Hospice, Loughborough

One day care team member/ Makaton teacher, Julie, walked into the busy dining room and noticed a child gesticulating to the man on her left. As she drew near the girl made eye contact with Julie. 'Look, I'm sitting next to the man', she signed. Julie asked if that was a good thing, and she replied 'yes!' Julie passed the message on to the man, who coincidently is also the CEO of Rainbows.

Since the care team member/ Makaton teacher started at Rainbows Children's Hospice she has used and developed her skills in Makaton to aid communication with many of the children and young people. She is now a qualified instructor and has taught Makaton to staff within the hospice.

4.3 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you provide translators to work with families, young people and children for whom English is not their first language?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Remember language barriers can make people stay away from using your services.
- ✓ Ensure that your telephone advice service also provides adequate language support.
- ✓ A good translator is regarded as someone who does more than change words into another language, and is someone who can empathise but also help with understanding policies and procedures. It is important that there is a robust policy to support staff and interpreters that enables translation to be accurate and effective.
- ✓ Only using trusted community advisors or family has limitations, as the advice or information given can be misleading. This needs to be balanced with what the individual wants and what information is needed to ensure adequate service access and planning.
- ✓ Remember, you may need to exercise your professional judgment on whether to use a translator even if a family declines, especially if you feel that the family is unable to provide the depth of detail needed due to language barriers.
- ✓ Keep adequate language resources at the hospice – books, tapes, toys – and ensure families and staff know where they are.
- ✓ Religious and cultural norms can mean that an inappropriate pairing of client/translator in some communities inhibits full discussion, for example men translating for women.
- ✓ Training in the basics of interpreting should be offered to those who regularly act as interpreters to promote best practice, especially if it is difficult to find professional interpreters.
- ✓ Try to work in partnership with diverse community organisations to develop your requisite knowledge and expertise in this area.
- ✓ Remember heavy reliance on family members to translate, as can happen, raises the issue of confidentiality and appropriateness, and also raises the issue that a relative or carer may filter, abbreviate or omit information.

4.4 g			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you have any service user representation of families from diverse backgrounds on the Board of Trustees?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Involving representatives from diverse families on the board of trustees provides a mechanism for increased choice and control and the ability to influence service development strategically. ✓ It is important to understand the time/resource limitations and training needs of individuals in encouraging board participation. There might be cultural/language issues that act as barriers.		✓ Do you actively seek to recruit trustees from diverse communities? ✓ Making and sustaining good community links is a good way to encourage community leaders and others to get involved at a trustee level.	

4.5 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Are families from diverse groups made aware of policies and protocols that promote equal service for all groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Providing adequate and accessible information on policies and practice is vital in empowering families and children to benefit from hospice services. ✓ Making families aware of any culturally specific policies and provision demonstrates a clear commitment to meeting their specific needs.		✓ Ensure the complaints procedure is also made public in a range of formats to enable effective use.	

4.6 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you offer specific support mechanisms to families from diverse backgrounds?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Developing a parents' support group that caters for particular language, cultural or disabled needs enables parents from excluded/minority backgrounds to participate fully in hospice life.
- ✓ Employing a dedicated staff member like a link worker to work with families with particular needs is good practice in offering valuable support and a first step to bring excluded communities within reach of hospice services.
- ✓ Offer practical support and advice on welfare benefits/rights, funeral costs, organ donation and tissue removal. For many BME communities options such as organ/tissue donation are often considered taboo and not encouraged.
- ✓ Ensure there is access and accommodation available for disabled family members.
- ✓ Remember, disability and illness have been traditionally viewed as a cause for shame and stigma within many BME communities and families need information and support to view hospice options differently.

Good Practice

Acorns Children's Hospice, Birmingham

Acorns Hospice has created a separate budget to provide resources to deliver some culturally appropriate provision. Items funded by this are religious artefacts, Asian newspapers, running the Asian Mothers' Group and newsletter, a staff training booklet on diversity, multi-faith festival calendars, multicultural CDs, DVDs, books, end-of-life care multicultural wall chart, Asian greeting cards.

Good Practice

Rainbows Children's Hospice, Loughborough

The play team plan certain events, displays and activities around the calendar. These include religious festivals as well as organised occasions and themed activities around different cultures. When planning these the team incorporate diversity into the scope and range of activities, and reflect the ability and age appropriateness of the experience for the children and young people.

Musical events have proved to be particularly enjoyable for all. Some of these have included a gospel choir, African drumming and a steel band.

Good Practice

A national free telephone help-line was developed by CancerBacup to provide accessible information for people (patients, carers and professionals) from a variety of ethnic backgrounds. The Cancer in Your Language service was designed to provide specialist nurses to put callers in touch with translators and respond to specific questions. This service could support more than 100 languages. Free help-line services were also available in twelve different languages (covering 60-65% of British ethnic minority communities). These included: Arabic, Bengali, Cantonese, French, Greek, Gujarati, Hindi, Polish, Punjabi, Turkish, Urdu and Vietnamese.

Source: Big Lottery Cancer Evaluation Report 2006

4.7 r

Question	Response	Evidence and supporting information	Follow-up action required
Is your family support able to meet the needs of smaller less visible, groups such as single-parent families and gypsy and traveller groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Single-parent families will often not have the resources to participate in different aspects of hospice life, and you will need to support them and get them involved in different ways – bearing in mind the potential constraints on their time and resources.
- ✓ In some diverse communities, a single women with a child needing end -of-life palliative care is often facing some stigma, shame and lack of wider family support.
- ✓ Gypsy and traveller communities are often large and tight knit, and the role the extended family/community plays in the life of the child needs to be understood and accommodated.
- ✓ The lifestyle and circumstances of some traveller communities may make it difficult for them to access hospice services, so you may need to reach out to them rather than wait for them to come to you.
- ✓ Romany gypsies belief in the supernatural, and fears about death play a significant role in their rites and customs related to dying and death. When a person is near death, an extensive ritualistic process is initiated.

4.8 r

Question	Response	Evidence and supporting information	Follow-up action required
Are there mechanisms in place to enable families from diverse backgrounds to fully understand their child's prognosis?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ Sometimes diagnosis and prognosis may be given to one parent who speaks English, excluding the non-English-speaking parent. This has ramifications, especially if the child's primary care giver is the non-English-speaking parent, in most instances the mother. ✓ In the healthcare setting, only the elder males from gypsy communities (Roma) are likely to communicate with healthcare personnel. A women is not permitted to interrupt men or to be alone with a man who is not her husband or relative. ✓ Staff attitudes and use of language/body language must be respectful and understanding of any barriers faced by families in communicating or understanding their child's condition. ✓ Some cultures may not allow pain control or blood transfusions. ✓ A belief that there is always a need to maintain hope for possibly a treatment or cure for a condition can be very strong amongst some diverse groups. For a parent to ask for support from a children's hospice service signals the loss of hope, and could also be seen as an admission of failure in their skills as a parent.	✓ In some diverse BME cultures the female members of the family are bound by the decision making of the male members of the family. Participation in a support programme for Pakistani and Bangladeshi families, for instance, often relied upon decision and approval of the father or extended family. Some mothers had their decisions overturned by a husband or father, which could cause communication problems with health and social care professionals.

4.9 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you show empathy and respect for rituals and traditions practised by diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Staff need adequate training to identify key rituals of individual families and their faiths, especially when offering ongoing and future bereavement support. ✓ Staff need awareness on diverse spiritual needs in providing support. ✓ Do staff maintain information and contact with BME funeral directors to support families at the time of bereavement? ✓ Develop new traditions that bring diverse communities together, such as Memorial Day to celebrate the lives of children that have died. Plan this in a secular fashion, with the use of different languages, music and food from different cultures.		✓ Draw up guidelines for spiritual care on different religious and spiritual beliefs as a basis for discussion. Base this on what is gathered from the local community and patients as well as source texts. This should include protocol for care of the dying: general considerations, diet, personal care, procedures on death, funeral protocols and post mortems. Make contact with temples, mosques and other places of worship to improve your knowledge of local community facilities. ✓ For many families, the crisis of advanced illness and death highlights traditions and rituals that offer meaning and support to them. It is now acknowledged that when properly assessed, heightened awareness of these cultural factors can influence the quality of care experienced.	

Cultural Practice

In gypsy (Roma) communities when a person is near death, a special candle is brought into the room. At the time of death this candle is lit and a window opened. It is believed that the candle will light the way to heaven for the deceased person's soul. The body is rubbed with holy oil, and the family displays intense grief. For three days, all Roma must grieve by remaining in the presence of the dead. During this time, they may decide not to bathe, shave, wear jewellery, change clothes or prepare food. They are allowed to drink coffee, brandy or other liquors. Mirrors may be covered and vessels containing water may be emptied.

Caring for dying relatives in the home environment when possible is a matter of honour for many families from different ethnic groups, as well as a means of ensuring that death occurs in a holy place. Within the Hindu tradition there is the concept of 'karma', meaning that a parent must be responsible for decisions made about the care of their child – including during their death – which could preclude the use of children's hospice services. Similarly, the care of relatives is seen as a sacred obligation for Caribbean families.

Good Practice

Acorns Children's Hospice, Birmingham

Acorns Children's Hospice has produced a series of booklets on cultural customs and religious practices for South Asian families, including guidance on meeting dietary needs and protocols on attending funerals. They have also produced a multi-faith end-of-life chart/poster that explains the different religious practices and customs of various faith groups.

Good Practice

Acorns Children's Hospice, Birmingham

Religious artefacts cupboards provide access to prayer beads, holy water, prayer mats, religious texts, head covers and prayer tapes for children, young people and the families of different faiths or denominations.

A number of children's hospices recognise the value of providing access to religious artefacts, and have placed cupboards in the main areas of the hospice reception and bereavement areas of the building.

Acorns and Rainbows Children's Hospice are just two hospices that provide artefacts cupboards for families. These area a cost -effective way to ensure secular organisations provide a sensitive and appropriate support to families from diverse community groups, who may find it comforting to have access to religious artefacts.

4.10 a			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does your organisation have established protocols around suspected abuse in diverse families or with children/ young people?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ It is important to raise the need for training and awareness of female genital mutilation issues within the profession and increase the knowledge of practising communities. Ensure that the safety of children remains paramount in discussions and interventions on female genital mutilation.		✓ Staff need to be able to deal with any incident of threatening behaviour, domestic violence or abuse (psychological, physical, sexual, financial or emotional) between adults who are or have been intimate partners, or to children, regardless of gender or sexuality. This includes issues of concern to Black and Minority Ethnic communities such as so-called 'honour killings' when individuals, particularly women, break traditional practice.	

4.11 a

Question	Response	Evidence and supporting information	Follow-up action required
Do you have adequate mechanisms to receive regular feedback from families, young people and children from diverse groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ These need to be frequent enough to gain a perspective on effectiveness of services, as well as to identify problems as soon as they arise.
- ✓ Group feedback via forums must take into consideration different languages (both written and spoken) and the needs of disabled families when attending these sessions.
- ✓ Group feedback must account for gender barriers where parents from some diverse communities may prefer to give feedback in same-gender gatherings.
- ✓ Surveys and questionnaires requiring written feedback must be made accessible to all diverse families and their particular cultural or physical needs.
- ✓ Timing and venue used for family consultation must account for cultural and physical access needs and barriers, ie having disabled access, understanding that some diverse communities will not attend a venue where alcohol is served, and not planning consultations on particular religious days, which prevents attendance.
- ✓ Consult parents from diverse groups who use hospice services about the current service and how it can be improved to suit their cultural needs.
- ✓ Encourage visits through open days to the hospice services by local diverse groups and communities; ask for their feedback on the appropriateness of facilities and environment of the hospice service for their cultural and religious needs.

Good Practice

Acorns Children's Hospice, Birmingham

Acorns Children's Hospice has in place an Asian Mothers' Support Group which provides culturally specific activities and support to women whose children use the hospice services. This greatly benefits the members who are able to meet other mothers with similar experiences, share advice and provide support to each other, have fun, and meet in a women-only environment that allows for greater involvement.

"It is very good emotional support; I get advice from the Cultural Link worker as well as other mums."

"Meeting other people. Mothers who get some time for themselves to come out and enjoy themselves."

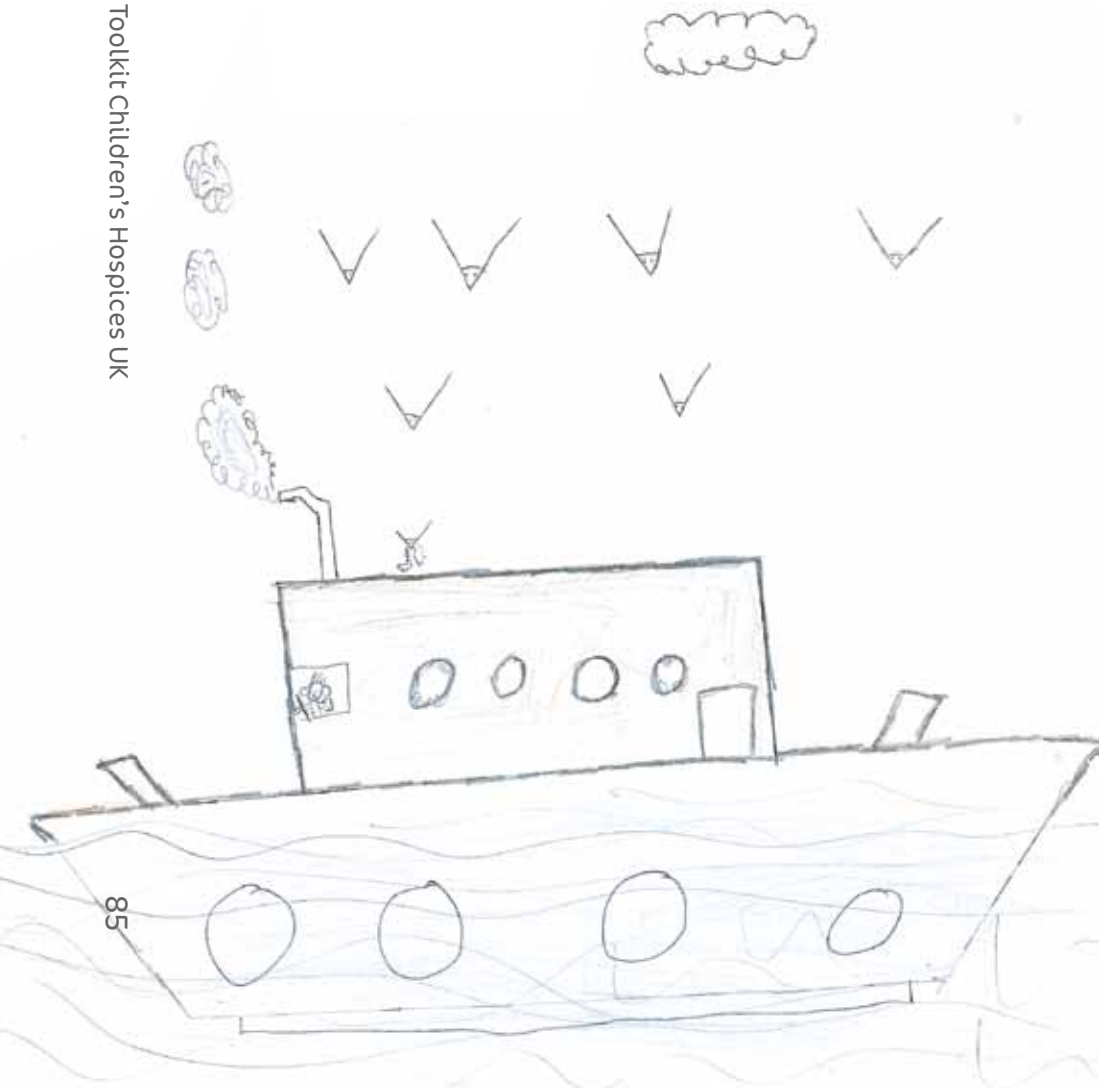
The group also includes children in their range of activities, so that family needs can be met fully. The mothers speak a variety of South Asian languages, and an interpreter is provided to accommodate any additional language needs.

Action Plan Worksheet For Modules

r – Immediate priority a – Moderate priority g – Long-term priority

Priority & Action Required	Resources Required	Achievement Indicators	Timescales	Staff Lead

Module Five
Monitoring



Outline

In order to establish how well services are being provided, and if those services are actually meeting need and aspirations, there is a necessity to establish and implement robust procedures of assessment and review of those services.

Monitoring will enable the organisation to identify gaps and weaknesses in service delivery and employment practices; and enable the organisation to put together an action plan to meet the needs of all service users, volunteers and employees.

This module aims to ensure the intelligent collection of monitoring data, with an understanding of its potential for service improvement. The module also aims to show you what to monitor and to conduct self-assessments of current performance in promoting equalities and diversity across the organisation and its services.

Monitoring requires you to standardise data collection and repeat the process for continuous improvement.

Awab Patankar, Age 8, Shooting Star Children's Hospice

5.1 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does the organisation monitor/assess 'how are we doing' in relation to the principles set out in its policies and practices?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ This gives the organisation an opportunity to identify areas of weakness. ✓ Enables the organisation to put its principles and policies into practice.		✓ The policies / practices / services to be reviewed will need to be prioritised in order of relevance.	

5.2 r

Question	Response	Evidence and supporting information	Follow-up action required
Does the organisation conduct an equality impact assessment of its policies and the services it delivers?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Conducting Equalities Impact Assessment (Eqla) will help organisations consider the needs, circumstances and experiences of the people (staff and service users) who will be affected by the main functions and policies.
- ✓ Identify inequalities in outcomes; including unlawful discrimination, which can be real or potential.
- ✓ Consider other ways of delivering a service, or achieving the aims of the policy, so that the impact is removed or minimised.
- ✓ Strive to ensure that monitoring and review of action plans is built into the performance management framework of the organisation, and then reported regularly to the executive, board or to elected members.
- ✓ Organisations will need to include information in their scheme(s) about what arrangements they have put in place to positively promote policy, practice and service delivery in respect of these areas.

5.3 r

Question	Response	Evidence and supporting information	Follow-up action required
Is this assessment all inclusive, ie does it cover age, race, gender, sexual orientation, disability, religion and belief?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ It is increasingly a legal requirement that employers are required to monitor and publish specific diversity data for their workforces, for example data by ethnicity, disability status and gender.
- ✓ All data collection must comply with the Data Protection Act 1998.
- ✓ It is important that data gathered must be adequate, relevant, accurate and stored securely.

- ✓ Referring to the seven equality strands can help to mainstream equalities and diversity, integrate policies and objectives with best value, encourage the development of good practice and provide a framework for improving performance.

5.4 r

Question	Response	Evidence and supporting information	Follow-up action required
Is information regularly collected on all large and small BME communities and other diverse ethnic groups?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Due to inward and outward migration, your client group is liable to constantly change.
- ✓ Build formal monitoring into existing record keeping tasks.
- ✓ Ensure client databases are regularly updated, thus integrating new knowledge with existing practice.

5.5 r

Question	Response	Evidence and supporting information	Follow-up action required
Do you make sure that the views of diverse groups are communicated to all management levels and departments in your organisation/team?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ In order to make real changes in the way diverse groups are provided for you may need extra resources and awareness from a range of levels within your team/organisation.
- ✓ Ensuring that the perspectives of these groups are disseminated within your team/organisation is a vital step in making change happen across the organisation.

5.6 r

Question	Response	Evidence and supporting information	Follow-up action required
Are your quality standards drawn from, or do they relate to, other statutory inspection measures, ie Supporting People Quality Assessment Framework (QAF), other review mechanisms for services for care services?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ Formulating quality standards based upon existing inspection measures will help improve the service you deliver and make inspections an opportunity to continually improve.

✓ It might be useful to do an external analysis to compare the organisation's quality standards with those of other organisations in the same field.

5.7 r

Question	Response	Evidence and supporting information	Follow-up action required
Does the organisation have a written complaints procedure?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ Does your organisation have a culture that invites comments, suggestions and criticisms?

✓ Often the only way that services can develop and change is through people taking issue with the current state of services. Each organisation needs a way in which these comments are heard, understood and dealt with.

5.8 r

Question	Response	Evidence and supporting information	Follow-up action required
Is this complaints procedure clear and available to diverse groups/communities?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ Remember, for various reasons diverse groups/communities may not find a complaints procedure accessible. Make sure the organisation takes appropriate steps to raise awareness of your complaints procedure amongst the whole of the community you serve.

5.9 r

Question	Response	Evidence and supporting information	Follow-up action required
Does the organisation have an action plan defining aims and strategies to improve related services for the next year and more?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ By devising an action plan, exploring the gaps in provision and identifying the needs and aspirations of BME service users, you will be able to plan how you are going to improve the lives of those the organisation works with.

5.10 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Will the organisation carry out an equality and diversity self-assessment?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ This exercise should include consulting service users, staff and volunteers.			

5.11 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do you have minority ethnic staff working in your organisation or team?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Members of diverse groups/communities report that they feel more comfortable conversing with people who are from their own ethnic group. ✓ Staff from minority ethnic backgrounds can bring a unique insight into how services should be delivered, and they can also help colleagues understand the diverse community in greater depth.		✓ However, it should not be assumed that staff belonging to a certain ethnic group have a sense of shared language, identity and understanding with the service user – the organisation may also need to consider other factors – around, faith and gender, for example – as well.	

Good Practice

Equality Impact Assessment (EqIa) results in an inclusive information and communications policy, and supports social cohesion

The EqIA of Fenland District Council's information and communication service has resulted in key changes. The review identified a range of needs for accessible information, with regard to community languages, Braille and Moon (a symbol-assisted language used by some visually impaired people), as well as the need to address low literacy among the local population as a whole. Actions stemming from the review included the provision of service information on CD or audio tape, which made a big difference with increased take up of, and satisfaction with, services.

Comprehensive equality monitoring in relation to service take-up, introduced at the same time, has ensured that information is gathered by geographic area and equality group. This information is used to identify gaps in service and inform service development and change. For example, consultation with users of parks and open spaces has led to the provision of basketball and netball courts. This was a specific request by members of migrant communities from Eastern Europe. Seeing games being played in the parks led to an interest in, and take-up of, these sports by other local people. This has made a significant contribution to social cohesion in the area.

Source: Equality and Human Rights Commission: 'Making Practice Happen' 2009

5.12 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Are there clear career paths, development opportunities and additional support for diverse staff?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ It is important to monitor the turnover rate of staff and, in particular, whether the organisation is losing diverse staff/volunteers. ✓ It is beneficial that the department/organisation conduct exit interviews to find out why staff/volunteers leave.		✓ Regular monitoring will ensure the development of a comprehensive and inclusive HR strategy. This should include recruitment, retention, development of a diverse workforce and collection of authoritative data.	

5.13 r

Question	Response	Evidence and supporting information	Follow-up action required
Have the services you provide been confirmed as accessible and appropriate for members of diverse groups/communities through service user surveys and questionnaires?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ Gaining feedback from those that you provide services for is a good way of assessing outcomes from the work that you do.

✓ It is important that the organisation considers accessible and appropriate ways in which this data can be collected.

5.14 r

Question	Response	Evidence and supporting information	Follow-up action required
Does the organisation take into account the fact that members of diverse groups/ communities might not be used to being asked about their views on services?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

✓ This may be the first time that their views have been sought about service provision – your questions may seem strange and may provoke initial suspicion of your intentions.

5.15 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does the organisation monitor how certain services – for example, preparation of meals, washing and personal hygiene, daily care etc – are received/perceived/ experienced by people from different ethnic backgrounds?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Certain services may need to be tailored in order to fit into the lives of a diverse client group.			

Action Plan Worksheet For Modules

r – Immediate priority a – Moderate priority g – Long-term priority

Priority & Action Required	Resources Required	Achievement Indicators	Timescales	Staff Lead

Module Six
Employment Practice, Policies and Legislation

Dana Shields, Age 10, Rachel House Children's Hospice

Outline

A significant effect of the various Equalities and Diversity and Employment legislation is that the organisation – and therefore its staff, volunteers and trustees have a duty and a responsibility to implement legislation and develop policies to promote effective – employment relations, workplace partnership and best practice.

This module aims to build an inclusive organisational culture characterised by good relations between people – staff and service users – from diverse groups and cultures, through raising awareness and understanding of some fundamental standards that should be present in all employment systems and practices. These include consistency across the organisation, adverse impact or disproportionate effect on members from diverse communities, accommodation of differences among employees and job-relatedness of departmental procedures.

6.1 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Is your organisation aware of all the relevant equalities and diversity and employment legislation?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ As a voluntary and community organisation you must operate within all the equalities and diversity legislation, just as you would any other legislation. That means that it is important that the organisation understands and recognises its legal responsibilities towards staff and volunteers.		✓ Organisations that see the legislation not as a burden, but as an opportunity to build on equality and diversity principles and increase employee and service user satisfaction, are more likely to experience improved financial and non-financial benefits.	

6.2 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does your organisation operate within and apply the legislation in respect of your employees, service users and provision of services?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Where organisations interact successfully with equalities and diversity legislation, they develop new skills and knowledge that enable them to anticipate and therefore to manage internal and external changes in respect of their employees, service users and service provision.
- ✓ Organisations that demonstrably embrace equality and diversity legislation will enhance their reputation and further develop employee and service user satisfaction.
- ✓ There is a strong business case for operating within and embracing equalities and diversity principles.
- ✓ The National Service Framework for Children (2004) – Standard 8 for instance, which builds on the five key outcomes laid down in Every Child Matters (2004) and the Children's Act (2004) – emphasises the importance of children's palliative care, including children's hospice services, being available to all young people who need them.
- ✓ PCTs, NHS Trusts and local authorities are required to ensure that their provision takes account of the young person's and their family's physical, emotional, cultural and practical needs.
- ✓ In November 2005 the DfES and the DoH published guidance for the commissioning of children's palliative care services. This stressed that there is a need for such services to be more systematically developed for all children and young people who require them.

6.3 r

Question	Response	Evidence and supporting information	Follow-up action required
Do your employees and trustees operate within equalities and diversity and employment legislation in the provision of services?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ It is important that the laws are explained and understood by all.
- ✓ It is the responsibility of everybody to implement good equality and diversity practices and be aware of their responsibilities in order to comply with the regulations and be accountable for what they do.

6.4 r

Question	Response	Evidence and supporting information	Follow-up action required
Does your organisation have vision, mission and value statements?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ These express the organisation's sense of purpose – the visions, the values and the strategic plan for its growth and development.
- ✓ Having a clear mission statement and strategic plan ensures that anyone at any level in the organisation should be able to describe how their job helps fulfil this and is consistent with the organisation's values – otherwise known as 'being in the loop'.
- ✓ In order to get 'buy in' to the mission statement, employees must know what the priorities are, be able to translate them into specific action and collaborate effectively.
- ✓ An organisation that creates a shared sense of mission is one where teams, departments and individuals are focused on their goals and are accountable.

6.5 r

Question	Response	Evidence and supporting information	Follow-up action required
Does your organisation have an Equality and Diversity Policy?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ An Equality and Diversity Policy is a statement of organisational intent. It is the written and visible manifestation of the organisation's approach to Equality and Diversity, and as such has major internal and external impact.
- ✓ For employees the policy should reinforce the values, mission and principles of the organisation and let them know what is expected in terms of their behaviours and attitudes towards each other and service users.
- ✓ The policy also enables the organisation to focus on and manage the Equalities and Diversity Legal Framework's seven equality strands – sex equality / race equality / disability equality / equality for Lesbian, gay and bisexual people / equality for transgender people / religion and belief equality / age equality.
- ✓ It is also important to recognise that the policy will impact upon other organisational policy and procedure. It therefore needs to be fully integrated into the work the organisation undertakes.
- ✓ Increasingly any funding application is expected to demonstrate a real commitment to equality and diversity polices and practices as part of the consideration process.
- ✓ The policy can help build trust with your service users.
- ✓ Does your organisation have a policy which embraces the employment and training of HIV-positive staff?

Good Practice

Staff Rights

As a matter of good practice, your organisation should have a clear policy on equality and diversity, enabling people from the widest range of backgrounds to join and progress through the organisation, and a zero-tolerance approach to unlawful discrimination, bullying and harassment. Your organisation should be knowledgeable about equality and diversity (with staff training available on these issues) and committed to working towards best practice for inclusive recruitment and development.

Source: Handbook to the NHS Constitution

Good Practice

Policy and Strategy

- Business plans take into account consideration of demographics and other relevant information
- Equality and diversity is referred to and incorporated within all of the organisation's policies and plans
- All staff/volunteers understand policies and plans for equality and diversity
- The diversity of the organisation's customer requirements influences business plans
- Equality and diversity policies are linked to the overall vision and mission of the organisation, and are systematically reviewed using wide consultation
- The outputs and outcomes of policies and plans are identified and systematically measured.

Source: © Crown copyright, 2006 The Cornwall Diversity Toolkit

6.6 r

Question	Response	Evidence and supporting information	Follow-up action required
Does your organisation recruit for and employ a diverse workforce of female and male staff, volunteers and trustees?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ By employing a diverse workforce, your organisation can tap into a rich source of cultural and social knowledge and expertise that can benefit working practices and service provision.
- ✓ It makes good business sense to encourage more people from diverse communities to work for your organisation.
- ✓ When recruitment systems and practices are open and fair organisations can recruit from a wider pool of knowledge, ideas and skills.
- ✓ It will foster trust for future consultations and will help to create supportive communities who will be advocates for any new service developments.
- ✓ The staffing of the hospice service should reflect the diversity of the area in which it is based.

Good Practice

LOROS (the Leicestershire and Rutland Organisation for the Relief of Suffering)

LOROS is a local charity set up to provide care for people throughout Leicestershire and Rutland with advanced incurable diseases, together with support for their families. It is non-religious, and funding is 60% NHS and 40% from charitable fundraising.

LOROS has no particular religious affiliation but spiritual care is an important part of the overall service provided.

Ethnicity data is collected at the point of referral. It is not complete but there is now a dedicated person who is overseeing this and going back to collect data, even if the patient has been discharged or has died.

Key success factors:

Work has been undertaken on raising awareness and understanding of cultural diversity amongst staff. At LOROS, they use the training manual from PROCEED - a multimedia training tool for educators within the health and allied professions which aims to help with the development of skills for responding appropriately to patient diversity by raising awareness and understanding of cultural diversity.

Staff recruitment initiatives to increase numbers of nurses from BME communities, although this has had limited success

"The hospice has a policy to recruit from the ethnic communities but there is a stigma attached to hospices in our culture and palliative care is definitely not attractive to them."

Outreach and community liaison officers - going out to communities to find out what their needs are, attend community meetings and raise awareness.

Access to interpreters, language support and advocacy services – ideally a dedicated support worker at the hospice with language skills.

Recruiting volunteers from the community

"Volunteers from the Asian communities have improved visibly. It is a very positive step. Culturally it is our duty to help and give to the needy. It is acceptable to fundraise, work in the shops in the community and for volunteer work such as driving."

Source: from Report by Social Research Network 2006

Good Practice

Cancerbackup and several of the BME projects working with the Chinese community reported a remarkable change in the uptake of services. The consensus view is that participation and attendance at sessions held to explain the cancer services, with the help of an interpreter, have increased, which is encouraging to note. Previously, people had stopped listening after a while and started playing mah-jong. Now they listen actively, ask questions and are keen to have more sessions. One project worker said: "The best experience is of working with the Chinese community."

Source: CancerBACUP 2004

Good Practice

Nottingham children's home-based scheme

Preparatory work for the design of a home-based scheme in Nottingham had identified few BME families taking up palliative care services. Recruitment of a BME project worker proved difficult but eventually the current post-holder was recruited. This worker has considerable experience, having a background in social services and good knowledge of the communities and local health and social care providers. Her first task was to undertake a mapping exercise and to introduce her role to health care professionals. One link provided six referrals immediately, but contact with consultants in the acute sector has not proved very productive to date. Cultural issues identified here include direct payments, so that families can access a worker who can speak their own language and provide appropriate hours at convenient times. Concerns also include knowledge of how to dress children in their ethnic attire and respecting the household by removing shoes on entry to the family home.

Source: Big Lottery Cancer Evaluation Report 2006

6.7 r

Question	Response	Evidence and supporting information	Follow-up action required
Do your organisation's employment systems - recruitment and selection procedures - comply with the principles of equality and diversity?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ It is important to ensure that all candidates are measured against the legitimate requirements/standards of the job. For example, personality traits such as "enthusiastic" and "dynamic" are difficult to define and measure consistently through job interviews.
- ✓ Ensure that tests prove competencies for the job, rather than testing for unrelated job requirements. For example, typing tests for jobs that involve little or no typing.
- ✓ Is success in test performance based on specific knowledge requirements or procedures for the job when these are not essential requirements for someone going into that position?
- ✓ Consult with organisations that have been successful in recruiting staff and volunteers from diverse groups.
- ✓ Promote your organisation as a fair, just and supportive place for people from BME communities to work.

6.8 r

Question	Response	Evidence and supporting information	Follow-up action required
Is the policy or practice likely to have a negative effect on people from diverse groups/ communities?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Negative effects often result from inappropriate selection criteria, eg inflated educational requirements.
- ✓ Are tests and other screening tools examined for cultural, gender and racial biases?
- ✓ Do the language, graphics or imagery used by the organisation exclude individuals from diverse communities such as gender, race, sexual orientation, disability, age, religion or belief?
- ✓ It is important to ensure that tests and other screening tools are free from any cultural, gender and racial biases. Non-job related or inappropriate selection criteria put in place to decrease the number of applicants may arbitrarily and consistently exclude qualified applicants. For example, requirements for years of experience may reduce the number of women applicants. Guard against excluding applicants who are perceived to be "overqualified" or whose work experience is not recent or has gaps.
- ✓ Develop an organisational strategy for the recruitment, training, career development and retention of staff and volunteers from BME communities.
- ✓ Although it is not a legal requirement for voluntary organisations as yet, it is good practice to implement an Equality Impact Assessment to determine whether a service, policy, procedure (whether planned or already in existence) is likely to have an adverse impact on any particular group of people due to their race/ethnicity, disability, gender, sexual orientation, age or religion/belief.

6.9 r

Question	Response	Evidence and supporting information	Follow-up action required
Do the organisation's formal or informal policies or practices restrict or exclude individuals from diverse communities from employment opportunities?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		

- ✓ Some employment practices are more informal or subtle and are based on traditional practice or departmental culture that is seldom written down or questioned.
- ✓ Physical barriers may affect people with disabilities - current as well as potential employees. For example, buildings and workstations may be inaccessible; job information may not be available in alternative media; facilities to interview, test or provide training may be inadequate.
- ✓ Barriers can also be created by the concentration of individuals from diverse communities at the lower levels of an organisation and in non-decision making positions.
- ✓ Endeavour to appoint senior staff and trustees from BME communities.
- ✓ Be aware that restrictions or exclusions can arise from the almost invisible and seemingly neutral practices entrenched in day-to-day operations. For example, things as simple as information about opportunities and application forms being available only in centralized or difficult to access locations, or not in the regions.
- ✓ Do individuals from diverse communities receive the same information given to or available to other employees? For example, who are the first to find out about possible vacancies? Are they considered for acting appointments, assignments, high-profile special projects, etc?

6.10 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does your organisation have a training and development policy that ensures equality of access?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ Some employees may only have access to training that is solely job-related, while others have access to job-related training as well as training that enables them to learn new skills for advancing in the organisation. ✓ Informal systems or misconceptions by managers may result in biased or unequal allocation of training and development opportunities and who gets to participate in conferences and seminars.		✓ It is important that the organisation consider that there may be a need for additional provision / special needs for targeted developmental training for employees who are from diverse communities.	

6.11 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Does the organisation have a Staff Training and Development Policy, and is it accessible and available to all?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ There may be a lack of diversity knowledge among staff and managers. Managers may not have the skills and/or received appropriate training to effectively manage and work with a multi-cultural, diverse work force. ✓ Does the organisation regularly provide training and information to educate staff at all levels about equality and diversity issues in the work environment?		✓ Train of all hospice staff and volunteers in multi-cultural and diversity issues, including racism and discrimination and especially in terms of the Children's Act 1989 Section 22, the Disability Discrimination Act 2005 and the Race Relations (Amendment) Act 2000.	

Good Practice

Staff, Volunteers and Trustees

- The organisation has conducted a comprehensive monitoring exercise of its people management practices and has made improvements based on the results of this
- The organisation has conducted assessments of its recruitment practices and outcomes and has made improvements to attract under-represented groups
- Staff surveys specifically include equality and diversity indicators, and improvements are made as a result of the feedback gained
- Internal procedures are evaluated for equality and diversity and are improved where necessary

- Documents such as staff and volunteer handbooks and training such as induction training promote the organisation's commitment to equality and diversity
- Training is provided for all staff, volunteers and trustees to highlight their rights and responsibilities.

Source: © Crown copyright, 2006 The Cornwall Diversity Toolkit

Good Practice

St George's Medical School

This project has produced a picture book in the Book Beyond Words series, telling the story of a woman who has cancer and needs treatment, to be used with patients who cannot easily read. Theatre production, workshops and a video about cancer were among other projects for an audience of people with learning difficulties. The project is also producing, piloting and evaluating training for professionals: distance learning unit for learning-disability care staff, accredited as part of the Learning Disabilities Awards framework, to be published and delivered by BDL; and training materials for professionals in cancer and palliative care, in conjunction with Macmillan Cancer Relief.

Source: CancerBACUP 2004

6.12 r			
Question	**Response**	**Evidence and supporting information**	**Follow-up action required**
Do all the staff and managers, including those in regional offices, have equal access to supportive training or programs for understanding and managing diversity?	◯ Yes ◯ Yes, partially ◯ No (please explain why not)		
✓ There may be a lack of diversity knowledge among staff and managers. Managers may not have the skills and/or received appropriate training to effectively manage and work with a multi-cultural diverse work force. ✓ Does the organisation regularly provide training and information to educate staff at all levels about equality and diversity issues in the work environment?		✓ Provide training as recommended by the NSF for Children's Services based on the National Workforce Competence Framework for Children's Services developed by Skills for Health and the Common Core of Skills and Knowledge for the Children's Workforce.	

Good Practice

St Gemma's, Leeds

St. Gemma's Hospice has operated as an independent charity from its foundation in 1978. Its development has been guided by the needs of patients.

In 1999/2000 proposals were submitted by St Gemma's and Sue Ryder Wheatfields to the Health Action Zone for funding of a Joint Leeds Hospices Ethnic Minority Project. This was active from 2001 to 2003. It was set up to address the perceived inequalities that BME groups experience within existing hospice services.

A project manager was funded for two years, together with four community workers representing the Bangladeshi, Pakistani, Indian, African Caribbean and Chinese communities to liaise with the hospices.

Specific activities have included:

A series of information evenings – such as Asian, Turkish, Polish and Chinese evenings – so that people could come and see the building. There are also links with local priests and rabbis and a key contact with the Sikh community.

Translation of information materials on hospice services into six languages (Urdu, Bengali, Hindi, Gujarati, Punjabi and Chinese) and dissemination to a database of people including GP practices, clinics, libraries, and community groups. Feedback has been positive.

Diversity training, initiated and carried out by a consultant. This is ongoing and now mandatory at St Gemma's for all staff. Diversity covers ethnicity, gender and lifestyle. A handbook on all the different religions and beliefs is available on each floor and is referred to frequently as well as being central to the training.

Source: Report by Social Research Network 2006

Action Plan Worksheet For Modules

r – Immediate priority a – Moderate priority g – Long-term priority

Priority & Action Required	Resources Required	Achievement Indicators	Timescales	Staff Lead

3.1 Resource Links

Advisory, Conciliation and Arbitration Service (ACAS)

ACAS aims to improve organisations and working life through better employment relations. It helps with employment relations by supplying up-to-date information, independent advice and high quality training, and working with employers and employees to solve problems and improve performance.

It is the employment relations service for England, Scotland and Wales offering practical, independent and impartial advice to employers, employees and their representatives. Acas encourages people to work together effectively, and aims to promote good practice in the workplace as well as helping to resolve disputes.

Further information can be found at:
http://www.acas.org.uk

Age Positive

A workforce that is age diverse has real benefits for any organisation. Harnessing the skills, experience and enthusiasm of people of all ages creates a working environment that encourages cooperation and has the potential to contribute to business at every level.

See also the government's Be Ready campaign

Further information can be found at:
http://www.businesslink.gov.uk
http://dwp.gov.uk/agepositive/

Association for Children's Palliative Care (ACT)

ACT is the only organisation working nationally to achieve the best quality of life and care for all children and young people who have a life-limiting or life-threatening condition and their families.

Further information can be found at:
http://www.act.org.uk/

Black Health Agency

Works to challenge inequalities in health through the development of good practice in developing services.

Further information can be found at:
http://www.blackhealthagency.org.uk/drupal/

British Dyslexia Association

Provides support and information to all those with dyslexia, as well as to professionals in health, education and employment.

Further information can be found at:
http://www.bdadyslexia.org.uk

Care Quality Commission

The Care Quality Commission is the independent regulator of health and social care in England.

Further information can be found at:
http://www.cqc.org.uk

Carers UK

Carers UK offers information and support on carers' issues to make life easier for the parent/carer and the person being cared for.

Further information can be found at:
http://www.carersonline.org.uk

Confederation of Indian Organisations

Works with the South Asian community in the UK and has a large representative membership.

Further information can be found at:
http://www.cio.org.uk/

Council of Ethnic Minority Voluntary Organisations

Further information can be found at:
http://www.cemvo.org.uk/

Department of Health

'Ten steps to your SES: a guide to developing a Single Equality Scheme'

Further information can be found at:
www.dh.gov.uk/en/Managingyourorganisation/ Equalityandhumanrights/ browsable/DH_066006

The Department for Work and Pensions (DWP):

- Promotes opportunity and independence for all
- Helps individuals achieve their potential through employment
- Works to end poverty in all its forms.

Further information can be found at:
http://www.dwp.gov.uk

Disability Rights Commission

Further information can be found at:
http://www.equalityhumanrights.com

The Disabled Living Foundation

Provides free, impartial advice about all types of equipment for disabled adults, disabled children, older people, their carers and families.

Further information can be found at:
http://www.dlf.org.uk

Down's Syndrome Association

The association provides information and support to all children and adults with Down's Syndrome, and for their families.

Further information can be found at:
www.downs-syndrome.org.uk

Dyslexia Action

A national charity and the UK's leading provider of services and support for people with dyslexia and literacy difficulties.

Further information can be found at:
http://www.dyslexiaaction.org.uk

The Employers' Forum on Age

Offers examples of bias-free application forms.

Further information can be found at:
www.efa.org.uk

Equality and Diversity Forum

Further information can be found at:
www.edf.org.uk

Equality and Human Rights Commission (EHRC)

The commission was established in October 2007, and replaced the previous equality bodies.

The commission is working to eliminate discrimination, reduce inequality, protect human rights and build good relations, ensuring that everyone has a fair chance to participate in society.

The commission brings together the work of the three previous equality commissions – the Equal Opportunities Commission, the Commission for Racial Equality, and the Disability Rights Commission. It also takes on responsibility for the other aspects of equality: age, sexual orientation and religion or belief, as well as human rights.

Further information can be found at:
http://www.equalityhumanrights.com/

Ethnic Jobsite

The Ethnic Jobsite was established in 2000. Working with the public and private sectors, the Jobsite is widely regarded as the leading job resource provider in the field. The Jobsite ensures that the best candidates are chosen for relevant roles, and strives to see that job placements in the UK provide an accurate reflection of diversity within British society.

Further information can be found at:
http://www.ethnicjobsite.co.uk

Every Child Matters (DCSF) 2005

Every Child Matters: Change for Children is a new approach to the well-being of children and young people from birth to age 19.

The government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well-being.

Further information can be found at:
www.everychildmatters.gov.uk

Every Disabled Child Matters (EDCM)

EDCM is a campaign by four leading organisations working with disabled children and their families to get rights and justice for every disabled child: Contact a family, Council for Disabled Children, Mencap and the Special Educational Consortium.

Further information can be found at:
http://www.edcm.org.uk
http://www.cafamily.org.uk
http://www.ncb.org.uk

Government Equalities Office

The Government Equalities Office (GEO) is the department responsible for equalities legislation and policy in the UK. The department was created by Parliament in October 2007.

The GEO is central to the Government's commitment to strengthen its ability to deliver across the entire equalities agenda.

Further information can be found at:
http://www.equalities.gov.uk

The Equality Bill: Creating A Fairer Society
Fact Sheet:
http://www.equalities.gov.uk/equality_bill.aspx

Ethnic Minority Women In The UK
Fact Sheet:
http://www.equalities.gov.uk/pdf/EthinicMinorityWomen.pdf

Hindu Council UK

Represents all the Hindu faith denominations in the UK, promotes an understanding of Hindu cultures and tradition as well as working to enhance interfaith mutual understanding.

Further information can be found at:
http://www.hinducouncil.org

Jewish Care

Provides care that recognizes the culture, traditions and beliefs that are frequently shared by Jewish people.

Further information can be found at:
http://www.jewishcare.org

Lesbian, Gay, Bisexual and Transgender

Web pages on Sexual equality resources from the Department of Health.

These pages provide a number of resources that will be useful for anyone responsible for ensuring that services do not discriminate against lesbian, gay, bisexual and transgender people.

http://www.dh.gov.uk/en/Managingyourorganisation/index.htm

Medical Foundation and Sexual Health

Promoting excellence in the prevention and management of HIV and other sexually transmitted infections.

Further information can be found at: **http://www.medfash.org.uk/links/alphalinks.htm**

Mencap

Provides information on health inequalities experienced by people with a learning disability.

Further information can be found at:
http://www.mencap.org.uk/

Mind (The Mental Health Charity)

Mind works for a better life for the estimated one in four people who will experience mental or emotional stress at some time in their lives.

Further information can be found at:
http://www.mind.org.uk

Multifaith Calendar

Holy days and festivals calendar.

Further information can be found at: **http://www.bbc.co.uk/religion/tools/calendar**

Muslim Council of Britain

Promotes cooperation, consensus and unity in Muslim affairs in the UK and works for the eradication of disadvantage and discrimination faced by the Muslim community.

Further information can be found at:
http://www.mcb.org.uk

National Service Framework for Children and Young People 2004

This ten-year programme is intended to stimulate long-term and sustained improvement in children's health. It aims to ensure fair, high-quality and integrated health and social care from pregnancy through to adulthood.

Further information can be found at:
http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Children/DH_108

Network of Sikh Organisations

Further information can be found at:
www.nsouk.co.uk

The Office for National Statistics

Produces independent information to improve our understanding of the UK's economy and society.

The Census in England and Wales
A census is a survey of all people and households in the country. It provides essential information from national to neighbourhood level for government, business and the community.

The most recent census was on 29 April 2001. Plans are being made for the next census to take place on 27 March 2011.

Further information can be found at:
http://www.ons.gov.uk/census/2011-census/index.html

Comparing census Data
A guide to comparing 1991 and 2001 census ethnic group data provides users with advice on using the 1991 and 2001 Census ethnic group questions to examine change in ethnic populations.

Further information can be found at:
http://www.statistics.gov.uk/cci/article.asp?id=1471

Focus on Ethnicity and Identity
Paints a picture of the ethnic groups in the UK today. It includes information on their characteristics, lifestyles and experiences; placing particular emphasis on comparing and contrasting the main groups.

Further information can be found at: **http://www.statistics.gov.uk/focuson/ethnicity/**

Office of Public Sector Information – Part of The National Archives Legislation

Legislation on this website is available as enacted in its original format and as revised text. Legislation published within the past two weeks and details about Acts awaiting Royal Assent can be easily found on the new legislation pages.

You can browse through alphabetical and numerical lists of Acts and Explanatory Notes and numerical lists of Statutory Instruments. These lists are grouped by the year the legislation was enacted or made. To browse through legislation use the navigation menu on the left side of the page and click on the area of legislation that is of interest to you. The navigation menu will expand to provide more options.

Original
Legislation in this section is as it was enacted. Statutes are published in HTML and PDF as they were originally made. No revisions or amendments have been made to the text. Visitors should therefore verify for themselves whether legislation is in force or whether it has been amended or repealed by subsequent legislation.

Revised
The revised legislation on this site is extracted from the UK Statute Law Database (SLD). By 'revised' we mean that the legislation is not

in the form in which it was enacted but incorporates subsequent amendments to the text and other effects with annotations.

Office of Public Sector Information – part of the National Archives.

http://www.opsi.gov.uk/ACTS/acts2000/20000034.htm

OFSTED

Inspects and regulates to achieve excellence in the care of children and young people, and in education and skills for learners of all ages.

Further information can be found at:
http://www.ofsted.gov.uk

Organ Donor

Each day, an average of 74 people receive an organ transplant. However, 17 people die each day waiting for transplants that can't take place because of the shortage of donated organs.

All individuals can indicate their intent to donate (persons under 18 years of age must have a parent or guardian's consent). Medical suitability for donation is determined at the time of death.

Successful transplantation is often enhanced by matching of organs between members of the same racial and ethnic group. Generally, people are genetically more similar to people of their own ethnicity or race than to people of other races. Therefore, matches are more likely when donors and potential recipients come from the same ethnic background.

Further information can be found at:
http://www.uktransplant.org.uk/ukt/

Rethink

Rethink is the largest severe mental illness charity in the UK.

Further information can be found at:
http://www.rethink.org

Royal College of Nursing

Meeting the health needs of people with learning disabilities, guidance for nursing staff (2006) Publication code: 003 024.

Further information can be found at:
http://www.rcn.org.uk

Royal National Institute For The Deaf

The Royal National Institute for the Deaf website can be found at http://www.rnid.org.uk

Royal National Institute for The Blind (RNIB)

Supports blind and partially sighted people.

The UK's leading charity offering information, support and advice to over two million people with sight loss.

Further information can be found at:
http://www.rnib.org.uk

Sensory Trust

The Sensory Trust promotes and implements an inclusive approach to design and management of outdoor space.

Further information can be found at:
http://www.sensorytrust.org.uk

Stonewall

Stonewall works to achieve equality and justice for lesbians, gay men and bisexual people.

Further information can be found at:
http://www.stonewall.org.uk

Terrence Higgins Trust

Delivers heath promotion campaigns and direct support to people who are at risk or living with HIV across the UK; especially people

from the African community, gay men and the people close to them.

Further information can be found at:
http://www.tht.org.uk

Travellers

You can access further information and links to other organisations on the gypsies and travellers website.

Further information can be found at:
http://www.gypsy-traveller.org

Working Families

Working Families helps children, working parents and carers, and their employers, to find a better balance between responsibilities at home and at work. The website introduces its work and offers information and helpful advice.

Further information can be found at:
http://www.workingfamilies.org.uk

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3.3 Glossary of Terminology

Access

This term denotes physical, cultural and/or social access for all staff and service users to all facilities and services. The promotion of equal access for all requires an understanding of the physical, cultural, linguistic, religious and social barriers that can prevent or inhibit participation. Legislation (and social policy) exists to remove or reduce certain barriers and to support positive action to improve access for disadvantaged groups.

Historically, the term has been used largely to mean physical access in relation to the barriers faced by disabled people. Improving accessibility has included making changes to buildings and also improving and extending the availability of accessible technologies.

It is important to recognise the barriers to access that are also faced by non-disabled people, particularly those from marginalised or minority groups.

African Caribbean

Individuals of African descent, who were born in the Caribbean.

Asian people

This collectively includes 'South Asian' and individuals who descend from the Indian subcontinent. This could include Asian, East African Asian, British Asian and people who originate from India, Bangladesh, Pakistan, Sri Lanka, Nepal or China.

Black and Minority Ethnic (BME)

Within a legislative context, there is no formal definition of this term. However, the term for the purposes of this tool is used to refer to all people who are members of minority ethnic communities whether they are visible minorities or not. The term therefore encompasses

all minority ethnic groups including non-white British groups, asylum seekers and refugees and gypsies and travellers.

Black

The use of the term black has changed over time. The term has been and still is used, variously, to describe some or all of the people of African, Caribbean, South Asian and other Asian origin, and often also to describe people of mixed heritage.

In recent years, the all-encompassing version of 'black' has been replaced by terms such as 'black and Asian' or 'black and minority ethnic' to indicate the range of ethnic backgrounds of those affected by prejudice, discrimination and racism.

The term has been challenged as a form of classification in the census and in ethnic monitoring which often adopts the census classification system.

Care of the dying

Care of the dying is the care of the child/young person and family in the last hours and days of life. It incorporates four key domains of care – physical, psychological, social and spiritual – and supports the family at that time and into bereavement.

Child *(see also Young person)*

A child is a young person aged up to their 19th birthday.

Children's hospice service

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both child and family - physical, emotional, social and spiritual - through a range of services. These include:

- 24-hour end-of-life care

- 24-hour emergency care
- specialist respite/short breaks care
- 24-hour telephone support.
- practical help, advice and information
- bereavement support
- support for the entire family (including siblings, grandparents and any extended family)
- provision of specialist therapies, including physiotherapy as well as play and music therapy
- provision to carers of information, support, education and training where needed. Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose-built building.

Children's palliative care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

The aim of palliative care is to achieve quality of life and a dignified death, preferably in a place of the child and family's choosing. All children with palliative care needs require an individual package of care, including variable components of both generic and specialist palliative care provided in a planned, coordinated, timely and flexible manner as directed by need.

Complex care/continuing care

Complex/continuing care is a bespoke package of care that enables the supportive and palliative care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and the provision of psychological, social, spiritual and practical support, as

well as core health services. It is provided to children with high levels of complexity or intensity of nursing care needs.

Culture

Shared rituals, symbols and ways of doing things that give a group its sense of identity.

Cultural competence

Refers to an ability to interact effectively with people from different cultures. Cultural competence comprises four components: (a) Awareness of one's own cultural worldview, (b) Attitude towards cultural differences, (c) Knowledge of different cultural practices and world views, and (d) Cross-cultural skills. Developing cultural competence results in an ability to understand, communicate with, and effectively interact with people across cultures.

Cultural racism

Cultural racism is revealed when a dominant culture imposes its values, beliefs and practices on others. It is influenced by a range of historical, social, political and economic factors. Where these behaviours involve unequal power relationships between individuals or groups from different cultural backgrounds, racist actions on the part of members of the dominant culture have the effect of marginalising those from immigrant and minority communities. This may be entirely unwitting, with the dominant culture taking it for granted that either there is no alternative view or that its assumptions should prevail.

Disability

The Disability Discrimination Act (1995) describes a disabled person as anyone with 'a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities'.

For the purposes of the Act:

- substantial means neither minor nor trivial

- long term means that the effect of the impairment has lasted

or is likely to last for at least 12 months (there are special rules covering recurring or fluctuating conditions)

- normal day-to-day activities include everyday things like eating, washing, walking and going shopping

- a normal day-to-day activity must affect one of the 'capacities' listed in the Act which include mobility, manual dexterity, speech, hearing, seeing and memory

- people who have had a disability in the past that meets this definition are also covered by the scope of the Act. There are additional provisions relating to people with progressive conditions.

The DDA (2005) amended the definition of disability. It ensured that people with HIV, cancer and multiple sclerosis are deemed to be covered by the DDA effectively from the point of diagnosis, rather than from the point when the condition has some adverse effect on their ability to carry out normal day-to-day activities.

This is intended to be a fairly wide definition. Physical impairments include sensory impairments such as those affecting sight or hearing and also medical conditions. Mental impairment covers a wide range of impairments relating to mental functioning, including what are often known as learning disabilities and also clinically well-recognised mental illness.

The barriers disabled people encounter can include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media - films, television and newspapers.

Discrimination

Discrimination occurs when prejudices and stereotypes prompt actions that result in less favourable treatment of individuals or groups. There are laws that prohibit both direct and indirect discrimination on grounds of race, gender, disability, sexual orientation, religious faith or belief and age.

Direct discrimination occurs when someone is treated less favourably than others on, for example, the grounds of race, ethnicity, disability,

age, gender, marital status, sexual orientation, religion or belief or other irrelevant criteria. For example, it is unlawful to decide not to employ someone, dismiss them, refuse to promote them, deny them training, give them adverse working conditions or deny them benefits based on such grounds.

Indirect discrimination occurs when an organisation has employment rules, selection criteria, policies and other practices, conditions or requirements which apply to all but in practice that organisation has a detrimental effect upon a group of individuals and cannot be fully justified.

Diversity

This term is relatively new in the 'equalities' landscape. Diversity is about recognising, valuing and taking account of people's different backgrounds, knowledge, skills and experiences, and encouraging and using those differences to create a productive workforce.

It refers to the recognition and value of an individual's uniqueness along dimensions of age, disability, ethnicity, gender, race or religious belief or faith, sexual orientation or socio-economic status.

The 'promotion' of diversity describes commitment to implementing the equalities legislation and often includes 'the business case'. This refers to the benefits to the business community of exploiting the changing demographics of the workforce to recruit and retain the highest calibre of staff.

Commitment to diversity recognises the existence of and the potential for discrimination and/or harassment based on, age, disability, ethnicity, gender, race or religious belief or faith, sexual orientation or socio-economic status. It is likely to include actions to challenge and minimise the likelihood of discrimination or harassment and to support and empower its victims.

Diverse groups

This includes a wide range of groups which define themselves on the basis of: Black and Ethnic Minority, religion, age, disability, gender, sexuality, gypsy and traveller, health, socio-economic status.

This describes other groups/communities apart from BME with particular needs to include gay and lesbian, gypsy and travellers,

disabled people and those with learning difficulties, single parents, women, and those with HIV.

End of life

The phase 'end of life' ends in death. Definition of its beginning is variable according to the individual child/young person and professional perspectives. In some cases it may be the child/young person or family who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the child/young person.

End-of-life care

End-of-life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both children and young people to be met. Children in long-term remission or following successful curative treatment are not included.

End-of-life care services

End-of-life care services are services to support those with advanced, progressive, incurable illness to live as well as possible until they die. Through core and universal health services it is provided to children with high levels of complexity or intensity of nursing care needs.

These are services that enable the supportive and end-of-life care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement.

It includes management of pain and other symptoms, and provision of psychological, social, spiritual and practical support. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

Equality

Basic equality is a cornerstone of the legislation promoting equality of opportunity and outlawing discrimination. It describes the commonly held view that human beings are entitled to a reasonable level of concern and respect.

In terms of challenging inequalities, treating people the same does not create quality of opportunity. Sometimes you have to treat people differently in the first instance in order to give them an equal opportunity to access all areas of life.

This may require making specific adjustments in order to aid particular individuals. This may then lead to equality of access, equality of opportunity, equality in relation to certain resources, and so on.

Equalities and diversity (previously known as Equal Opportunities) monitoring

This is used to assess the effectiveness of an Equality Policy as well as recruitment and selection procedures. Employers have a responsibility to ensure equality of opportunity for all staff, and monitoring is important in fulfilling this obligation.

Ethnic group

Everybody belongs to an ethnic group. People's ethnicity includes their history, language, beliefs, religion, nationality and geographical region. Accordingly, ethnic groups that are in the minority are commonly referred to as ethnic minority groups or minority ethnic groups.

The latter term is often preferred as it attributes the minority status to the ethnicity of the group rather than to the group itself.

Increasingly the term 'black and minority ethnic' (BME) and 'diverse communities / groups' are used to describe ethnic groups that are either numerically small or disadvantaged and subject to possible discrimination and racism.

Ethnic minority

A person or group of people who have a different culture, religion or language to the main one in the place or country where they live.

Ethnicity

A strict definition of an ethnic group is a group regarded as a distinct community by virtue of certain essential characteristics – a shared history which distinguishes it from other groups and a cultural tradition of its own. The expression 'ethnic monitoring' is used in reference to groups defined by colour, race or national origin as well.

Family

The term 'family' includes parents and other family members involved in the care of the young person, or other carers who are acting in the role of parents (Skills for Health, CYP08, 2006). 'Family' includes informal carers and all those who matter to the child/young person.

Family needs should be identified and met throughout the last phase of life and into bereavement. This includes management of pain and other symptoms and the provision of psychological, social, spiritual and practical support.

Gender

The word 'gender' is often used in place of the word 'sex' in equality issues. 'Gender' does not appear in legislation (except for 'gender re-assignment' – see below) but 'sex discrimination' and 'gender discrimination' are generally interchangeable.

Gender reassignment

Gender reassignment is a process undertaken under medical supervision for the purpose of reassigning a person's sex by changing physiological or other characteristics of sex.

Genuine occupational requirements *(see also Employment legislation)*

The Sex Discrimination Act, Race Relations Act, Religion or Belief Regulations and the Sexual Orientation Regulations allow for circumstances where a person's sex, racial group, age, disability, religion or sexual orientation is a genuine requirement for a particular job.

An employer is allowed when recruiting for a post to treat job applicants differently if possessing a particular sexual orientation, or religion, or belief is a genuine occupational requirement for that post.

This must be a genuine and determining factor, but it cannot be used to discriminate. An employer may also rely on this exception when promoting, transferring or training persons for a post.

For example, it would be a genuine occupational requirement to request an individual to provide personal services to people from a particular racial group, defined by colour or nationality, in order to promote their welfare, which tends to be something that a person of the same colour or nationality can do most effectively.

Gypsies and travellers

There are 200,000 -300,000 travellers in England. The largest group are Romany gypsies, who have been in England since the early 16th century. Irish travellers have also been in England since the 1800s. Both Romany gypsies and Irish travellers are recognised in law, in the shape of the Race Relations (Amendment) Act 2001, as separate racial groups. Note: It is inappropriate to use ‘gypsy’ as a derogatory term.

Harassment

This term denotes unwanted conduct that violates people’s dignity or creates an intimidating, hostile, degrading, humiliating or offensive environment on grounds of race or ethnic origin, age, disability, gender, sexual orientation, or religion or belief.

Harassment is a form of direct discrimination. For example, behaviour which is unwelcome or unacceptable and which results in the creation of a stressful or intimidating environment for the victim amounts to harassment. It can consist of verbal abuse, racist jokes, insensitive comments, leering, physical contact, unwanted sexual advances, ridicule or isolation.

Such behaviour can be persistent or an isolated incident, and can involve one or more individuals.

Hospice at home

Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at home works in partnership with parents and families and other carers.

Human rights *(see also Human rights legislation)*

Human rights are basic rights and freedoms which all humans are entitled to. They are things like the right to life and liberty, freedom of thought and expression, and equality before the law. To violate someone's human rights is to treat that person as though they are not a human being.

Institutional racism

This is best defined by the description in the Macpherson Report into the Steven Lawrence Inquiry: "Institutional racism is the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people. It persists because of the failure of the organisation openly and adequately to recognise and address its existence and caused by policy, example and leadership". *[Macpherson Inquiry report: Chap 6, 6:34]*

Key working

Key working, or care co-ordination, is the name given to an integrated service in which two or more agencies work together to support disabled children and young people and their families. It encompasses individual tailoring of services based on assessment of need; inter-agency collaboration at strategic and practice levels; and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one (Care Co-ordination Network UK, 2006).

Key worker

A key worker is both a source of support for disabled children and young people and their families and a link by which other services are accessed and used effectively. Key workers have responsibility for working together with the family and with professionals from services and for ensuring delivery of an inter-agency care plan for the child and family (CCNUK, 2004).

Learning disability and learning difficulty

Learning 'disability' is described by the Department of Health as "a state of arrested or incomplete development of mind which began in childhood and which includes significant impairment of intellectual and social functioning" (DH 2001), otherwise described as "a reduced ability to understand new or complex information (impaired intelligence) and reduced ability to cope independently (impaired social functioning) which began before adulthood and which has a lasting effect on development". (DH 2004)

A learning 'difficulty', however, normally denotes specific problems such as dyslexia and dyspraxia.

It is somewhat confusing that many practitioners use the terms interchangeably to describe a lifelong condition rather than specific difficulties of learning.

LGBT (see also Sexual orientation)

This is a commonly used collective acronym for lesbian, gay, bisexual and transgender people.

Life-limiting conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancers affecting children. Children in long-term remission or following successful curative treatment are not included.

Mixed ethnicity, mixed race, dual/mixed parentage/heritage

These terms describe people who are of mixed ethnic origin. Some people may prefer to identify themselves as 'black' or 'white' or according to their cultural or ethnic origins, rather than some sort of mixture. 'Half caste' should be avoided, as this is offensive.

Palliative care

The aim of palliative care is to achieve quality of life and a dignified death, preferably in a place of the child and family's choosing. All children with palliative care needs require an individual package of care – including variable components of both generic and specialist palliative care – provided in a planned, coordinated, timely and flexible manner as directed by need.

Personal racism

Personal racism can have a significant effect on reproducing inequalities, particularly if the individual concerned is in a position of power – for example, teachers over students, senior managers over staff and people who have control over the allocation of resources. It includes racist abuse and racial harassment; physical attack; allowing personal assumptions, prejudices or stereotypes to influence recruitment and selection of staff or students; and collusion with the tolerance of racist language and jokes.

Prejudice

Natural prejudices are in all of us, as a result of early upbringing in the home, social conditioning and life experiences through school to the workplace.

However, pre-judging without having correct information can lead to unfair actions.

Race

The term ‘race’ was used historically as a way of categorising individuals and population groups, usually in a way that asserted white supremacy. It is not based on any biologically valid distinctions in the genetic make up of differently identified ‘races’. Accordingly, it has no validity as a distinguishing description of an individual or group, although the ethnicities of individuals and groups may be different.

Nevertheless, the term prevails in the ‘race’ relations legislation and in the associated duty for organisations to have equalities and diversity policies and to challenge racial discrimination and racism.

Racism *(see also Prejudice)*

Refers to the ideology of the superiority of one particular ethnic or cultural group over another. The notion of superiority is expressed through beliefs, attitudes and behaviours that perpetuate injustice and prompt discrimination. It can occur at different but interrelated levels.

Respite care *(see Short break/specialist respite care)*

Sexual orientation

Sexual orientation describes the sexual attraction between individuals as follows:

- Heterosexual/straight: attracted to those of the opposite gender
- Lesbian (women) or gay (men): attracted to those of the same gender
- Bisexual: attracted to others of either the same or different gender.

Assumptions and perceptions of a person’s sexuality are also covered by law.

Sexism/sexist

Sexism refers to behaviour that comes from the belief that because you are a particular gender you are better than someone who is a different gender.

Short breaks/respite care

Short breaks/respite care is care where the three main functions are:

- to provide the child or young person an opportunity to enjoy social interaction and leisure facilities
- to support the family in the care of their child at home or in an alternative community environment such as a children's hospice
- to provide opportunities for siblings to have fun and receive support in their own right.

Short breaks/respite care may offer the whole family an opportunity to be together and to be supported in the care of their child, or it may offer care solely for the child or young person.

Specialist respite care

Specialist respite care refers to a setting of care, a programme of care or a service that provides additional services. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist respite care provides support required to meet the child's holistic care needs, and enables children and families to access short break services. Specialist respite care will often address some aspects of symptom management.

Specialist respite care should also meet the functions described under short breaks/respite care.

Stereotyping

A stereotype is a simplified and fixed idea of how people belonging to a group behave. It is usually based on opinion rather than evidence.

Supportive care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people who have a life-threatening illness. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised.

Symptom management

Symptom management is the control of the physical aspects of symptoms combined with attention to the psychosocial and spiritual elements.

Transgender *(see also Gender re-assignment)*

Gender describes our identity as a woman or man. For most people it coincides with the biological sex ascribed at birth. For a minority who are transgender, their internal sense of identity is different from the sex ascribed at birth and from how others perceive them. A transgender person may decide to go through transition and move from their assigned gender to their inner one. They may or may not choose to have hormone treatment and/or surgery as part of this. Someone who is transgender may be straight, lesbian, gay or bisexual. Transgender people are protected under the Sex Discrimination (Gender Reassignment) Regulations of 1999.

Vicarious liability

Employers have legal liability for any act of discrimination (including harassment) carried out by their employees unless the employer can show that they have taken all reasonably practicable steps to prevent it.

Employees also have a legal responsibility to respond and act appropriately in the course of their employment with an employer.

Victimisation

Victimisation is treating people less favourably because of something they have done under or in connection with the equalities

legislation, eg made a formal complaint of discrimination or given evidence in a tribunal case. Victimisation can also be suffered by those who have championed or supported someone else who has made a complaint about harassment or victimisation.

Link: The Guidance about Compliance offers guidance based on the draft regulations which were published on 30 March 2009 (Link to regulations: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097141).

Volunteer

A volunteer is a person who voluntarily performs or offers to perform any non-compulsory activity or service which involves spending time, unpaid, doing something which aims to benefit others (excluding relatives), society or the environment.

Appendix 1
Legislation

Equalities and Diversity Legal Framework

There are seven equality strands and (currently) ten principal pieces of equalities legislation that outlaw discrimination and promote equality of opportunity for people from the seven equalities groups.

The seven equality strands are:

- sex equality
- race equality
- disability equality
- equality for Lesbian, gay and bisexual people (LGB)
- equality for transgender people
- religion and belief equality
- age equality.

The most important pieces of legislation covering equalities issues are:

- The Equal Pay Act 1970
- The Sex Discrimination Act 1975 plus the Sex Discrimination (Amendment) Act 1985 and the Gender Reassignment regulations 1999
- The Race Relations Act 1976 and Race Relations (Amendment) Act 2000
- The Disability Discrimination Act 1995 and 2005

- The Human Rights Act 1998
- The Employment Equality (Sexual Orientation) Regulations 2003
- The Employment Equality (Religion or Belief) Regulations 2003
- European Commission Goods & Services Directive 2004/113
- The Equality Act 2006
- The Employment Equality (Age) Regulations 2006

A significant effect of all of the various Equalities and Diversity-related legislation is that the organisation and therefore its staff have a duty and a responsibility to promote good relations between people from diverse groups.

Discrimination

Discrimination in the context of Equalities and Diversity legislation refers to treating a person less favourably, directly or indirectly, due to or as a result of their:

- race and ethnicity
- gender
- disability
- sexual orientation
- religious beliefs
- age.

Differences can also lead to some people experiencing discrimination due to their:

- educational background
- work experiences
- income
- parental status

- marital status
- political beliefs.

Aim to build a non-discriminatory, inclusive culture, characterised by good relations between people – staff and service users – from diverse groups and cultures.

Legislation

- The Civil Partnership Act 2004
- Disability Discrimination Act 1995
- Disability Discrimination Act 2005
- Employment Equality (Age) Regulations 2006
- Employment Equality (Religion or Belief) Regulations 2003
- Employment Equality (Sexual Orientation) Regulations 2003
- Equality Bill 2009
- The Equal Pay Act (as amended) 1970
- The Equality Act 2006
- The Equality Act (Sexual Orientation) Regulations 2007
- The Gender Recognition Act 2004
- The Human Rights Act 1998
- Race Relations Act 1976
- Race Relations (Amendment) Act 2000
- The Racial and Religious Hatred Act 2006
- The Sex Discrimination Act (as amended) 1975
- Sex Discrimination Act 1975 (Amendment) Regulations 2008
- Sex Discrimination (Gender Reassignment) Regulations 1999

The Civil Partnership Act 2004

This Act creates a new legal relationship of civil partnership, which two people of the same sex can form by signing a registration document. It also provides same-sex couples who form a civil partnership with parity of treatment in a wide range of legal matters with those opposite-sex couples who enter into a civil marriage.

Further information can be found at:
http://www.opsi.gov.uk/acts/acts2004/ukpga_20040033_en_1

Disability Discrimination Act 1995

Disability is a physical or mental impairment which has a substantial and long-term adverse effect on someone's ability to carry out normal day-to-day activities.

The Disability Discrimination Act 1995 (DDA 1995) is a law that makes it illegal to discriminate against disabled people.

Under the DDA 1995 discrimination can occur when: a disabled person is treated less favourably than someone else; the treatment is for a reason relating to the person's disability; this treatment cannot be justified.

The DDA requires employers, service providers and those in education to make "reasonable adjustment" for a disabled person. Failure to do this may also be discrimination.

Further information can be found at:
http://www.opsi.gov.uk/acts/acts1995/1995050.htm

Disability Discrimination Act 2005

The Disability Discrimination Act 2005 extends coverage of the DDA 1995 to 'point of diagnosis' for some conditions, eg mental health disability does not have to be 'clinically well recognised'.

The DDA 2005 also places a duty on all public authorities, to promote equality of opportunity between disabled persons and other persons. It requires public authorities to:

- publish and monitor a three-year action plan
- undertake disability monitoring of staff and service users

- undertake disability equality impact assessments on all services and policies

- consult with service users and the public from disability groups when developing services and policies; and publish results of these consultations and service audits

- train staff on these general and specific duties.

Further information can be found at:
http://www.opsi.gov.uk/ACTS/acts2005/20050013.htm

Employment Equality (Age) Regulations 2006

These regulations outlaw discrimination (direct discrimination, indirect discrimination, harassment and victimisation) in employment and vocational training on the grounds of age.

These regulations came into force in October 2006.

Further information can be found at:
http://www.opsi.gov.uk/si/si2006/20061031.htm

Employment Equality (Religion or Belief) Regulations 2003

These regulations outlaw discrimination (direct discrimination, indirect discrimination, harassment and victimisation) in employment and vocational training on the grounds of religion or belief.

The regulations apply to discrimination on grounds of religion, religious belief or similar philosophical belief.

Further information can be found at:
http://www.opsi.gov.uk/si/si2003/20031660.htm

Employment Equality (Sexual Orientation) Regulations 2003

These regulations outlaw discrimination (direct discrimination, indirect discrimination, harassment and victimisation) in employment and vocational training on the grounds of sexual orientation.

The regulations apply to discrimination on grounds of orientation towards persons of the same sex (lesbians and gay men) and the same and opposite sex (bisexuals).

Further information can be found at:
http://www.opsi.gov.uk/SI/si2003/20031661.htm

The Equal Pay Act (as amended) 1970

This Act gives an individual a right to the same contractual pay and benefits as a person of the opposite sex in the same employment, where the man and the woman are doing the same work; or work related as equivalent under an analytical job evaluation study; or work that is proved to be of equal value.

Further information can be found at:
http://www.equalities.gov.uk/what_we_do/women_and_work/equal_pay.aspx
http://www.opsi.gov.uk/si/si2003/20031656.htm

The Equality Act 2006

One of the main features of the Equality Act 2006 was the establishment of the statutory basis for the creation of the Equality and Human Rights Commission.

The new commission was established in October 2007 and it replaces the previous equality bodies.

Further information can be found at:
http://www.equalityhumanrights.com
http://www.equalities.gov.uk/equality_bill.aspx

As well as establishing the Equality and Human Rights Commission, the Act:

- makes it unlawful to discriminate on the grounds of religion or belief in the provision of goods, facilities and services, education, the use and disposal of premises, and the exercise of public functions

- enables provision to be made for discrimination on the grounds of sexual orientation in the provision of goods, facilities and services, education, the use and disposal of premises and the exercise of public functions

- creates a duty on public authorities to promote equality of opportunity between women and men ('the gender duty'), and prohibit sex discrimination and harassment in the exercise of public functions.

It also places a duty on public authorities to produce:

- a Gender Equality Scheme - including the publication and monitoring of a three-year action plan
- undertake monitoring of staff and service users by gender
- undertake gender equality impact assessments on all services and policies
- consult with service users and the public with regard to gender when developing services and policies
- publish results of these consultations and service audits
- train staff on these general and specific duties.

Further information can be found at:
http://www.opsi.gov.uk/ACTS/acts2006/pdf/ukpga_20060003_en.pdf

The Equality Act (Sexual Orientation) Regulations 2007

The Equality Act (Sexual Orientation) Regulations came into force in April 2007.

The regulations protect individuals from discrimination on grounds of sexual orientation, in the provision of goods, facilities, services, education, the disposal and management of premises and the exercise of public services. Sexual orientation means an individual's sexual orientation towards:

- people of the same sex as him or her (gay or lesbian)
- people of the opposite sex (heterosexual)
- people of both sexes (bisexual).

The protection will therefore apply to everyone, whether they are lesbians, gay men, heterosexual or bisexual.

Further information can be found at:
http://www.opsi.gov.uk/si/si2007/em/uksiem_20071263_en.pdf

Equality Bill 2009

The Bill will simplify the law which, over the last four decades, has become complex and difficult to navigate. Written in plain English it will make it easier for individuals and employers to understand their legal rights and obligations.

The Equality Bill will:

- make Britain more equal, and help build a stronger society and economy for the future

- significantly strengthen and streamline discrimination legislation, replacing nine major pieces of legislation and about 100 other measures, spanning some 40 years

- require key public bodies to seriously consider what action they can take to reduce the socio-economic inequalities people face; ban age discrimination outside the workplace against people aged 18 and over; require organisations to report on gender pay

- the majority of the Equality Bill will be brought in to force in autumn 2010

Further information can be found at:
http://www.equalities.gov.uk/

The Gender Recognition Act 2004

The purpose of this Act is to provide transsexual people with legal recognition in their acquired gender.

Further information can be found at:
http://www.opsi.gov.uk/acts/acts2004/ukpga_20040007_en_1

The Human Rights Act 1998

The Human Rights Act came fully into force in October 2000. It gives further effect in the UK to rights contained in the European Convention of Human Rights.

The Act:

- makes it unlawful for a public authority to breach Convention rights, unless an Act of Parliament meant it could not have acted differently

- means that cases can be dealt within a UK court or tribunal; and says that all UK legislation must be given a meaning that fits with the Convention rights, if that is possible.

Further information can be found at:
http://www.opsi.gov.uk/acts/acts1998/ukpga_19980042_en_1

Mental Capacity Act 2005

This received royal assent on 7 April 2005 and was fully implemented on 1 October 2007. Overall, the Act provides a much clearer legal framework for people who lack capacity and those caring for them – by setting out key principles, procedures and safeguards.

Further information can be found at:
http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityAct2005/DH_073511

Race Relations (Amendment) Act 2000

The general duty is to promote race equality by:

- Eliminating unlawful racial discrimination.

- Promoting equality of opportunity.

- Promoting good relations between persons from different racial groups.

The Act also requires all public authorities to publish a Race Equality Scheme and sets a number of specific duties as well:

- Publish and monitor a three-year action plan.

- Undertake ethnic monitoring of staff and service users.
- Undertake race equality impact assessments on all services and policies.
- Consult with service users and the public from BME groups when developing services and policies.
- Publish results of these consultations and service audits.
- Train staff on these general and specific duties.

Further information can be found at:
http://www.opsi.gov.uk/ACTS/acts2000/20000034.htm

Race Relations Act 1976

The Race Relations Act (RRA) makes it unlawful to treat a person less favourably than another on racial grounds. These cover grounds of race, colour, nationality (including citizenship), and national or ethnic origin.

The Racial and Religious Hatred Act 2006

In October 2007, the Racial and Religious Hatred Act 2006 came into force.

This Act amends the Public Order Act 1986, and creates offences related to the stirring up of hatred against persons on religious grounds.

This has application both to the actions of individuals and to organisations.

Further information can be found at:
http://www.opsi.gov.uk/acts/acts2006/ukpga_20060001_en_1

The Sex Discrimination Act (as amended) 1975

This Act (which applies to women and men of any age, including children) prohibits sex discrimination against individuals in the areas of employment, education and in the provision of goods, facilities, and services and in the disposal or management of premises.

Further information can be found at:
http://www.opsi.gov.uk/si/si2003/20031657.htm

Sex Discrimination Act 1975 (Amendment) Regulations 2008

In 2007 the High Court found that UK sex discrimination legislation did not comply with European requirements. As a result the Sex Discrimination Act 1975 (Amendment) Regulations 2008 amends the Sex Discrimination Act 1975 (SDA) with effect from 6 April 2008.

The Amendment:

- introduced a revised definition of sex-related harassment
- imposed liability on institutions (and other employers) for sex/sexual harassment where they knowingly fail to protect an employee from repeated harassment by third parties
- extended the right of protection from pregnancy/maternity discrimination
- improved rights during compulsory and additional maternity leave, including removing the distinction between ordinary and additional maternity leave in respect of entitlement to non-pay benefits.

Further information can be found at:
http://www.opsi.gov.uk/si/si2008/uksi_20080656_en_1

Sex Discrimination (Gender Reassignment) Regulations 1999

These regulations are a measure to prevent discrimination against transsexual people on the grounds of sex in pay and treatment in employment and vocational training.

They effectively insert into the Sex Discrimination Act a provision to extend the Act, insofar as it refers to employment and vocational training, to include discrimination on gender reassignment grounds.

Further information can be found at:
http://www.opsi.gov.uk/si/si1999/19991102.htm
http://www.equalities.gov.uk/what_we_do/gender_reassignment.aspx

Additional Guidance for Northern Ireland

It is acknowledged that much of this list relates to diversity practice legilisation in England. Scotland and Wales generally interpret national guidance set by UK government, whilst Northern Ireland has a comprehensive framework of equality and anti-discrimination law which dates back to 1970 when equal pay legislation was first introduced. More recently, the Equality Commission was established in 1999 under the Northern Ireland Act 1998. It took over the powers and functions of the three predecessor Commissions and the Northern Ireland Disability Council. Section 75 of the Northern Ireland Act introduced new duties on public authorities to promote equality of opportunity and good relations on a range of grounds.

In 2000 the Equality Commission in Northern Ireland was given new responsibilities, powers and functions in relation to disability discrimination. Three important pieces of legislation were introduced in 2007:

- New disability duties on public authorities came into force on 1 January 2007 under the Disability Discrimination (NI) Order (DDO) 2006. These require public authorities to develop disability action plans which set out how they will promote positive attitudes towards disabled people and encourage the participation of disabled people in public life.

- The Equality Act (Sexual Orientation) Regulations 2006 make it unlawful to discriminate on grounds of sexual orientation in the provision of goods, facilities and services, education and public functions.

- Further provisions of the DDO 2006 have come into force. From 31 October 2007, people who are diagnosed with conditions such as cancer, MS and HIV are protected from disability discrimination from the point of diagnosis. People with mental ill health no longer have to prove that their condition is "clinically well recognised" to qualify as a disabled person.

Appendix 2

Equalities and Diversity Quiz Answers:

If you have got most of the answers right, well done as you already have a good knowledge of equalities and diversity.

If you haven't done so well, or if you struggled with answering some of the questions, don't worry, as this quiz is designed to raise your awareness of what equalities and diversity covers.

Q1 A

Q2 B

Q3 C

Q4 B

Q5 C

Q6 B

Q7 B

Q8 C

Q9 A

Q10 A

Appendix 3

A Guide to Writing an Equality/Diversity Policy

Policy documents commonly incorporate two main sections. First should be a statement of intent and the principles justifying your approach to equality and diversity. This should be followed by a more detailed section which sets out the organisation's aims and objectives. The policy can cover the following areas:

- a positive statement or vision of where your equality and diversity journey is intended to lead

- guidance on any acts that will constitute infringements against the policy, and the consequences of this – eg the organisation's approach to tackling discrimination in line with any relevant legislation etc

- a policy should be inclusive – it should be for everybody and should encompass under-represented groups in terms of race, faith, gender, sexual orientation, disability, age, etc.

- state the use of the policy, in terms of its application to relations with staff, volunteers, potential recruits, suppliers and customers.

It can also:

- reference other documents and policies, especially action plans and policies covering issues such as staff discipline

- identify a champion or person with overall responsibility for implementation

- include a statement on the review process for the policy.

Note the following:

- an effective policy needs the common ownership of the organisation – so get employees and volunteers to contribute to and improve the content

- a policy means nothing if it does not have a mechanism to deliver its principles

- policy works where it grows out of the norms of an organisation
- review and improve policy regularly to make it a ‘living document’
- integrate your equality and diversity policy into the staff and volunteer induction and other processes that establish the ground rules of operation within your organisation.

Appendix 4

Sample Statement on Equalities and Diversity

..... is mindful of its duties and obligations under Equalities and Human Rights legislation and is committed to improving the quality of its services to all people, irrespective of race/ethnicity, disability, gender, religion or belief, age or sexual orientation.

We will take action, individually, collectively and in partnership with others, to raise standards and make our services culturally appropriate, relevant and accessible to meet the needs of the people we serve.

We will take action to recruit and promote people from all backgrounds, at every level and across all professions, because of the additional value, knowledge and personal qualities their diversity brings.

We will take action to ensure that staff employed by ..... are culturally competent and treat every person with dignity, respect and fairness, in a way that is sensitively responsive to differences and similarities.

We will take action to put into practice systems, policies, and procedures which challenge discrimination and are fair, flexible and supportive to all who are affected by them.

We will encourage a culture of openness and reach out positively to the diverse local communities that we serve, to encourage and support their involvement in the review, evaluation and development of our services.

We will demonstrate our commitment through our actions, and we will communicate our intentions and our actions throughout our workforce and the communities we serve.

..... recognises that due to discrimination people may experience particular inequalities in accessing ..... services. The ..... objective is to deliver high quality services that are accessible, responsive, and appropriate to meet the diverse needs of different groups and individuals. Unlawful discrimination and other forms of exclusion have no place within.....

(Taken from the NHS Equalities and Diversity Strategy 2005)

Appendix 5 (A)

Diversity Toolkit Training Programme

10.00 am	Arrival and introductions
10.15 – 11.00	Introduction to the diversity toolkit/how to use it
11.00 – 12.30	Small group sessions: completing the modules
12.30 – 1.30	Working lunch
1.30 – 2.30	Evaluation questionnaire
2.30 – 3.00	Group discussion and feedback
3.00 pm	Close

Appendix 5 (B)
Children's Hospices UK Toolkit Training Slides:

Toolkit Aims:

- to enable you to have a better understanding of how to use the toolkit
- to provide you with an opportunity to apply your knowledge, skills and abilities in completing the modules.

Toolkit Objectives:

By the end of the day you will have:

- completed a module relating to your professional work area
- identified potential conflicts and knowledge gaps and developed resolutions to manage them.

Toolkit Outcomes (1):

At the end of the day we will ask you to:

- feed back on the processes used in the toolkit
- feed back on the content.

Toolkit Contents (1):

Section 1

1.1 Foreword

1.2 Acknowledgements

1.3 Glossary of Terms

1.4 Background and Key issues

1.5 How to use the Diversity Toolkit

1.6 Diversity Quiz

Toolkit Contents (2):

Section 2 – Modules

Module 1: Equality and Diversity Monitoring and Data Collection

Module 2: Collaboration and Community Links

Module 3: Service Planning and Access

Toolkit Contents (3):

Section 2 – Modules

Module 4: Listening to Children and Families

Module 5: Monitoring

Module 6: Employment Practice, Policies and Legislation

Toolkit Contents (4):

Section 3

3.1 Resources and key contacts

3.2 References

Appendices:

1. Employment legislation

2. Quiz answers

3. Guide to writing an Equality and Diversity Policy

4. Sample Statement of Equalities and Diversity

5. Toolkit implementation/training guidance (a), (b), (c)

ACTION PLANNING for Modules:

(R)ed – Immediate priority requiring immediate action.

(A)mber – Moderate priority requiring action over the medium term.

(G)reen – Long-term priority requiring action longer term.

Appendix 5 (C)
Children's Hospices UK Toolkit Evaluation Questionnaire

Date of Workshop: _____

Trainer's Name: _____

We would appreciate it if you could take the time to complete this Toolkit evaluation form so that your thoughts and comments can be considered.

How did you find the mix of participants in the workshop?

Was the language used in the Toolkit easily understood, for ease of implementation by different staff in your organisation?

Did you find the section on 'How to Use the Toolkit' useful?

Did you find the process to complete the modules useful and how? Please list any difficulties.

Did you find the modules you completed relevant to your work? Please explain.

Did you find the good practice examples useful and relevant, and if so why?

Did you find the process to action plan useful and why? Please list any barriers/difficulties.

Did you find the resources list in section 3 useful and relevant to your work? How might you/the organisation be able to develop it for local use?

Would you consider using the Toolkit in your organisation in the light of what you have learned today? Why?

Will you be able to implement the toolkit/action plans in your organisation in the light of what you have learned? Please outline any barriers/issues both within the Toolkit and within the organisation that you can identify.

Would you require any training to be able to effectively use the Toolkit within your organisation? Why?

Would you recommend a Toolkit workshop to your colleagues and why?

What is your overall assessment on the workshop?	◯ Very good ◯ Good ◯ Fair ◯ Poor

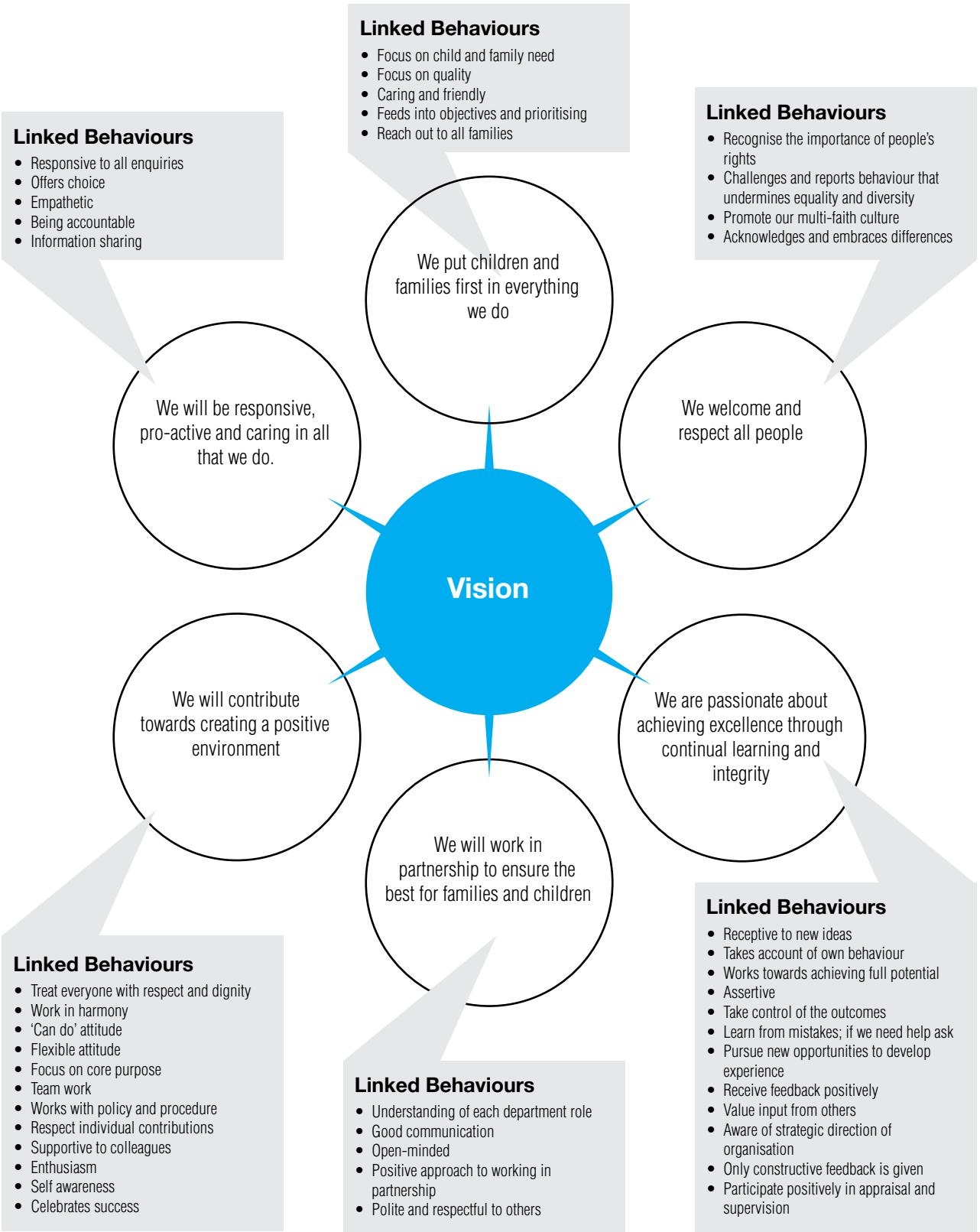
Any additional comments:

Name: _____

Name of Hospice: _____

Role: _____

Appendix 6
Vision Behaviour Model



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