

NBCP Bereavement Care toolkit

Supporting diverse families



national bereavement
c a r e p a t h w a y
for pregnancy and baby loss



Introduction

In this toolkit, we look at the principles of providing **inclusive bereavement care**. We explore the ways in which bereavement care services can meet the needs of all families who need to use them, without assuming a 'one size fits all' approach.

If you are a professional providing care for any family who has experienced pregnancy loss or the death of a baby, this toolkit is for you.

Please note, while throughout this toolkit we use the language of parenthood, we recognise that not everyone who has experienced a perinatal bereavement will identify as a parent. We encourage all staff to follow the lead of the people experiencing the bereavement. Mirror their language, and if you are in doubt about how they would like to be referred to, ask.





Diverse families

What do we mean by diversity? Diversity can mean different backgrounds and perspectives, different experiences of loss, and different family formations.

Families are diverse and this toolkit is here to help you reflect on providing a high-quality bereavement care service that is inclusive for all. **There is no one 'type' of bereaved family.**



Diverse families

Services are often designed with a stereotyped family in mind. This 'standard' family is often imagined as headed by a two-parent heterosexual couple who are white, able-bodied, financially secure, and whose genders correspond with the sex they were assigned at birth.

By assuming this is the norm, we exclude families who don't neatly fit into this shape from the services we provide. The reality is that many families do not look like this, and even if they do, we might be making all kinds of assumptions about what matters to them.

Our understanding of family is shaped by our own experiences, family structures and family roles, and we all carry biases about who a typical family is.





Diverse families

Who a family is may involve different family structures and diverse experiences. These may include:

- single parent families
- separated parents
- same-sex or same-gender parents. The gestational parent may not be the biological mother, and/or each may have been gestational parents of different children in forming the family
- more than two parents being identified by the family
- families where the gestational parent is a father
- families whose older children have been taken into social care
- parents who have themselves been or are currently in care
- siblings with different parents, including older children living with an adult who does not have parental responsibility
- close friends
- multigenerational households
- faith groups
- support networks such as advocates

Adapted from: [‘Involving and supporting partners and other family members in specialist perinatal mental health services’](#) (2021).



Mapping the family

There may be a range of people in a bereaved parent's family and wider support network who are important to their wellbeing, as well as needing support themselves.

- Mapping a family and support network can help identify who a parent relies on for support, and who might be involved in their bereavement journey.
- Ask open questions to discover who is in the family system and who is important to the parent. Stay curious and try to avoid making assumptions.

- This can help a parent define to you what relationships matter most to them.
- It can also help you learn about the culture, beliefs and values within the family system so you can provide more personalised care.

Activity

- Take a look at page 15 of this good practice guide [‘Involving and supporting partners and other family members in specialist perinatal mental health services’](#). Use the prompts to write down a list of open-ended questions you could ask a bereaved parent about their family and the support they might need. Who is in the family system, and how do they experience these relationships?



Inclusivity

Inclusivity in bereavement care involves creating an environment where all families feel seen, heard and respected.

Being curious about an individual family and open minded about who and what may be important to the parent or parents is central to inclusive care.

Activity

- [Listen to healthcare professionals discuss providing 'personalised bereavement care' in this NBCP video.](#)





Inclusivity

Being curious means being aware of:

- cultural considerations, for example how a family's culture understands a pregnancy loss or baby death.
- cultural assumptions as professionals, for example recognising and reflecting on our own unconscious biases.

Working in this way is also important for addressing inequalities.

The [NHS Constitution](#) sets out the legal duties for organisations in England to address inequalities in service delivery. These include:

Principle 1: the social duty to promote equality and reduce health inequalities.

Principle 3: to treat patients and staff with respect, dignity, compassion and care.





Moving from Equality to Equity

Equality is about ensuring that everyone, regardless of their background, circumstances, or experiences, receive the same level of care and assistance when dealing with the trauma of baby loss.

However, support shouldn't be a one size fits all approach.

- Everyone's experience of loss is different.
- People grieve differently.
- People face different barriers to accessing support.
- People experience different barriers in life.

Equity is about providing a fair and equal bereavement care service based on a person's individual needs and circumstances.

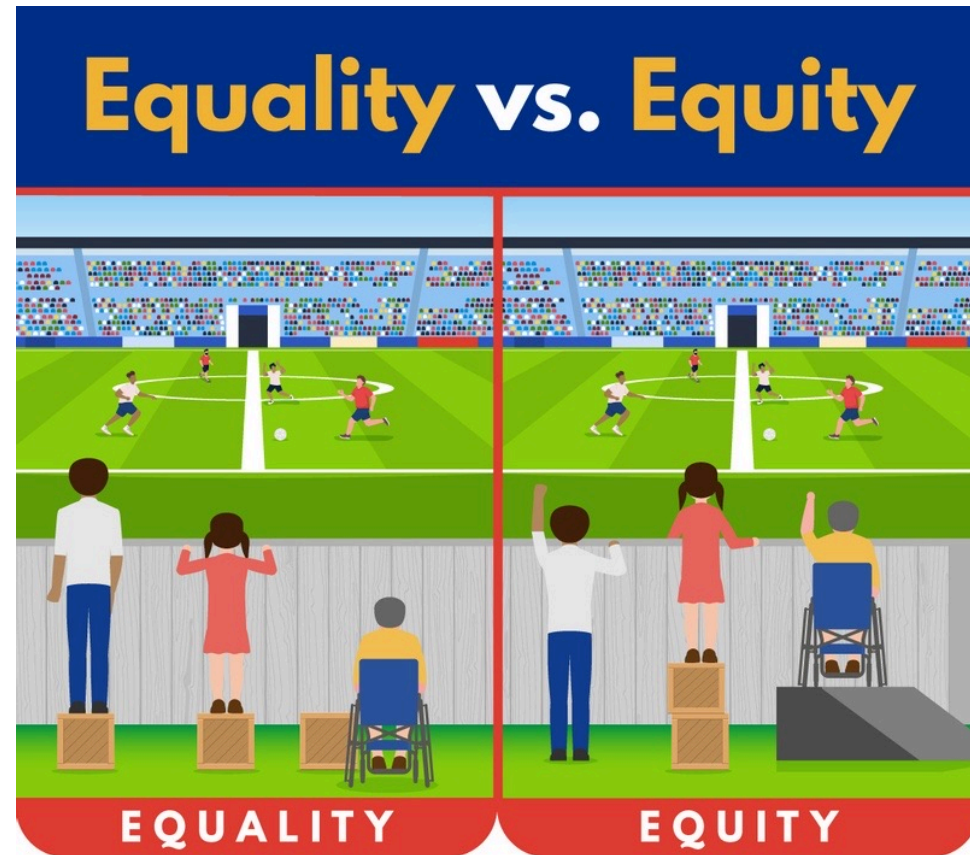


Image source: givetheunitedway.com/equity-vs-equality/

Reflecting on privilege

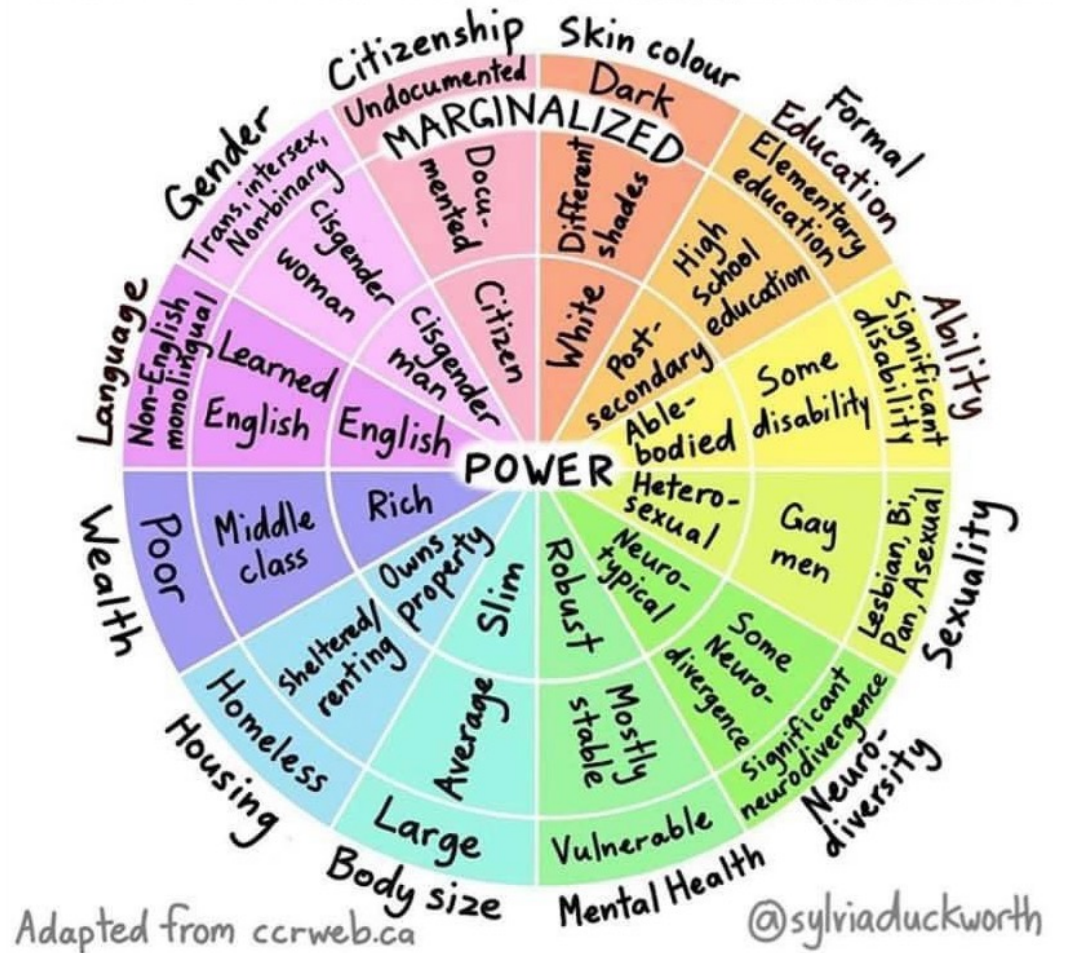
The **Wheel of Privilege** can help identify where someone sits on a spectrum of power. It shows how different parts of someone's identity can give them privilege in society, as well as lead them to experience exclusion.

Those mostly in the innermost ring tend to hold the most power. Their opinions will be the most listened to and they can navigate services with relative ease.

Those in the middle ring often experience a significant degree of exclusion and erasure.

Those mostly on the outermost ring tend to be the most marginalised and experience systemic discrimination.

WHEEL OF POWER/PRIVILEGE





Reflecting on privilege

When bereavement care services are designed for people who generally occupy the centre of the wheel, this actively excludes people from the outer rings. The further someone is out from the centre of the wheel, the harder they have to work to be included in the service being offered.

Activity

- Using the picture on the previous slide, take a look at the wheel to identify your level of power and privilege. Write down your level in each category.
- The closer to the centre of the wheel you are for each category, the more power you are likely to have.
- Does it surprise you to learn how privileged or marginalised you may be?



Reflecting on privilege

- Can you reflect on how a particular part of the service you offer may be available or accessible to someone who mainly occupies the outer wheel?
- Reflecting on a specific point of the wheel of privilege – for example, wealth and levels of deprivation – think about what barriers might exist to people accessing services. What could you do in your service to overcome some of these?

Activity

- [Watch this BBC Bitesize video of John Amaechi talk about privilege.](#)





Listening to families

Being curious about someone and their own unique bereavement journey, as well as considering the ways in which they might experience different forms of discrimination, is key.

Your own assumptions about who someone is might affect the ways in which you interact with that person, establish trust, and shape their experience of care.

This is stark when we consider the disproportionate number of families from marginalised groups who experience pregnancy loss and baby death.

Listening to families

In the following slides we're going to reflect on some of the ways in which people experience exclusion from bereavement services. It's important to remember that, as we've seen on the wheel of privilege, and as you likely experience in your own life, multiple identities can interact. The principles we are discussing around **listening to families** can be used to support all marginalised groups.





Listening to families: ethnicity

In the UK, reports show that rates of pregnancy loss and baby deaths are higher among Black and Asian babies compared with white babies. These differences have been evident for decades, yet there has been little progress in addressing them.

- [MBRRACE-UK data from 2022](#) shows that Black babies were over twice as likely to be stillborn compared with white babies, and Asian babies were almost 50% more likely to be stillborn. Black and Asian babies are also over 50% more likely to die shortly after birth compared with white babies.
- **This is unacceptable. No baby should have an increased risk of dying because of their race or ethnicity.**
- Ethnicity is not genetic. There is no single gene or group of genes that makes a person Black, Asian, or white. Health inequalities arise from systemic issues, including racism. It's not that Black and Asian women's bodies are less able to have babies.



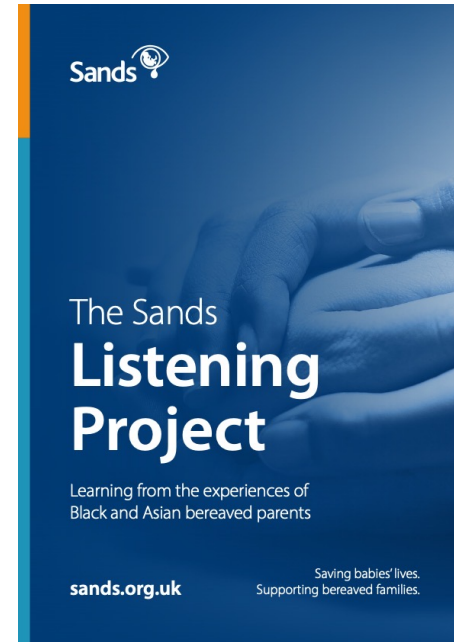


Listening to families: ethnicity

The **Sands Listening Project** (2023) heard specifically from bereaved Black and Asian parents, learning about their experiences of care, and their view of what needs to change.

[You can read the report here](#)

- Half of the participants believed they received worse care or were treated differently by healthcare staff because of their ethnicity. This included instances of racist stereotyping, behaviours, and language.
- The report shows that systemic issues, along with poor practice and discrimination from some healthcare professionals, may lead to less safe care, with devastating consequences for some Black and Asian families.



Activity

- Listen to the words of [Amber](#), [Vaishali](#) and [Daniel](#) who shared their stories of baby loss in the Listening Project.



Listening to families: LGBTQI+ community

Gender and sexual orientation impact a family's journey through conception and pregnancy.

Many LGBTQI+ parents will already have experienced discrimination in their lives and in making their family before they experience a bereavement.

It's important to understand that LGBTQI+ parents may experience additional kinds of emotional stress because they may be navigating a service where they are being made to feel 'different' and where their parenthood isn't recognised.

Activity

- Watch the ['It's OK to Ask the LGBTQI+ Community'](#) video





Listening to families: LGBTQI+ community

“

“One of the things that was so affirming was that it was treated as our loss, that my partner was equally respected in the situation, and we were a couple who had lost a baby, rather than myself having to go through it and my partner being just another person along the way.”

“

“Because we were both so recognised as the parents of this baby, that helped us. We weren’t in the midst of grief and having to navigate as a same-sex couple, we were just a couple who had lost, so I think that was brilliant.”

Source: [‘It’s OK to Ask the LGBTQI+ Community’](#) video



Listening to families: LGBTQI+ community

Ask what words someone would prefer and how they would like to be referred to.

Be led by the language parents use, and if you're not sure, it's okay to ask.

The language you use in your service, and the facilities and resources that are provided, might not meet the needs of LGBTQI+ families accessing your services. Are the words you use based on the assumption there is a 'mum and dad'? Are there forms and documents that only use the language of 'mother and father'?

People feel validated when they recognise themselves. Having images around your space that represent different families can help people feel that they belong, that they matter, and that the service is there for them too.





Listening to families: neurodiversity

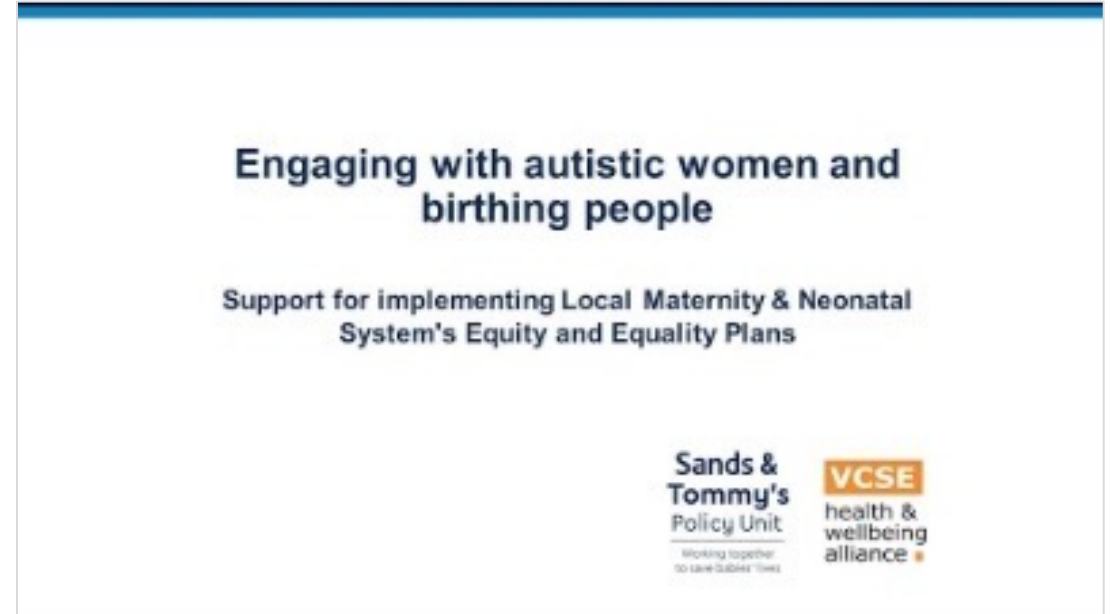
Neurodiversity is an umbrella term for a range of different thinking styles affecting how someone communicates with the world around them. It can include autism and ADHD.

- Neurodiverse parents tell us that healthcare services can be challenging to navigate. Hospitals can be overstimulating and overwhelming environments to be in.
- Neurodiverse parents may experience additional kinds of emotional stress from having to navigate an environment they find overwhelming as well as the trauma of a bereavement.





Listening to families: neurodiversity



Activity

- Watch this [‘It’s OK to ask about autism’](#) video.
- Listen to this [Maternity Consortium discussion](#) on providing equitable services for autistic women and birthing people.

Reflecting on these videos, what kinds of adjustments could you offer to a neurodiverse bereaved parent accessing your service?

Listening to families: young parents

Young parents can face additional challenges in accessing care and support, including discrimination because of their age.

Young parents may be needing to work exceptionally hard to access care. Making sure that the care you provide is parent centred, no matter their age, will help younger parents feel listened to and safe to ask questions.

Activity

- [Listen to parents discuss their experiences of maternity care in this Lullaby Trust video guide for health professionals on working with young parents.](#)



Listening to families: religion and faith

Religion and spiritual community can form an important part of parent's identity.

Understanding and being sensitive to religious rituals is central to providing culturally competent care. However, it's also important to avoid assuming that a parent's religion will automatically lead to specific preferences or practices.

Building a good relationship with your hospital chaplains will help support parents, as well as support you and your colleagues in providing culturally competent care.





Listening to families: religion and faith

Activity

- Access NHS England's Cultural Competency and Cultural safety e-learning [here](#).
- Watch this [Maternity Consortium video](#) on engaging with faith groups.
- Listen to Seyi discuss their experience in this [Sands video](#) for Black Maternal mental Health Week.



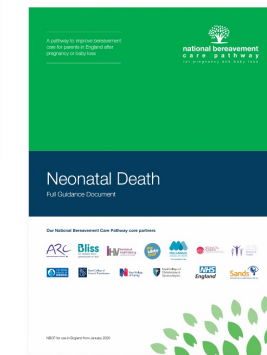
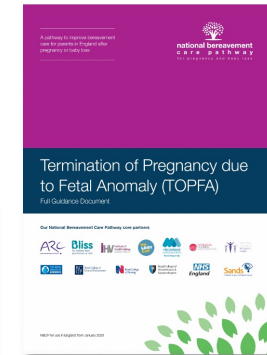
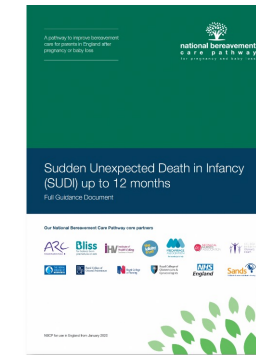
Listening to families: diversity of loss

We also need to recognise that there is diversity in people's experiences of pregnancy loss and baby death.

- The NBCP recognises five distinct experiences of pregnancy loss and baby death: miscarriage and ectopic pregnancy, TOPFA, stillbirth, neonatal death, and SUDI.
- These different experiences of losses do not create a hierarchy of bereavement and grief.
- The gestational age of the pregnancy or age of the baby does not equate to a specific amount of grief someone may experience.
- Specific experiences of loss come with their own challenges.
- Every family's bereavement journey is unique.

Activity

- Access training to learn about or refresh your understanding of different kinds of perinatal loss. [Sign up to a free Sands training webinar on understanding perinatal loss in a healthcare or community setting.](#)





Further resources

- [Sands supports anyone affected by pregnancy loss or the death of a baby, including professionals providing bereavement care](#). Sands provides specialist [support for Black families](#) and specialist [support for South Asian families](#) in recognition that both communities often face [additional barriers to support](#). Please follow the links for more information.
- The Maternity Consortium has produced a series of videos exploring engaging different communities in service development. [Access the videos here](#).
- NHS Suffolk and North East Essex has produced a series of 'It's OK to Ask' films exploring cultural curiosity within maternity care. [Access the full suite of these films here](#).
- [The VCSE Health and Wellbeing Alliance Resource Library](#) includes publications on health inequalities and maternal health.

We will continue to update this toolkit. If you have ideas for further resources to use, please contact us via bereavementcare@sands.org.uk.

Thank you



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NBCP is led by



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