



Irish Neonatal Health Alliance Submission to the Department of Children, Equality, Disability, Integration and Youth Public Consultation on the Development of a National Model of Parenting Support Services

April 2020

About the Irish Neonatal Health Alliance (INHA)

The Irish Neonatal Health Alliance (www.inha.ie) is a registered charity (CHY 21984, RCN-20100100). Our mission is to partner with, educate and empower families, healthcare professionals, educators, political decision makers and industry stakeholders on issues relating to the neonatal field.

INHA is grateful for this opportunity to put forward the particular support needs parents whose baby is born too soon.

Timely referral process to community supports

In Ireland, the average length of time that an infant spends in the neonatal unit is between 60 and 70 days. In recent years there has been a positive shift in Irish neonatal unit towards recognising the family as an integral component of high-quality neonatal care and procedural changes to implement Family Centred Care have been rolled out in all Irish neonatal units.

However, timely access to community-based supports such as those being offered by the INHA are a key determinant of successful outcomes for babies. Given the magnitude of the impact of being born too soon on a child's life and their families life, meeting the physical and mental health needs of the families whose baby is in the neonatal unit or has left the neonatal unit is an increasing challenge. Timely referral to supports services that the INHA can offer is not happening enough and many families are not receiving the support that they need in a timely fashion, which is directly impacting on the outcomes for premature babies.

INHA rely on neonatal staff to direct families to our services but with no clear guidelines or processes in place this often does not happen. This means that families, after discharge are being left to their own devices and many families are not receiving community supports that will ensure that their baby is followed up and can access early intervention sooner rather than later.

Mother's who are pregnant with a high-risk pregnancy where their baby or babies could be born too soon should also be referred in a timely manner to supports organisation such as the INHA for anticipatory support services.

The Department of Children, Equality, Disability, Integration and Youth needs to ensure that a family and baby centric approach is adopted in neonatal units, which ranges from diagnosis and treatment as well as increased referrals to community-based supports such as those offered by the INHA. Each unit must have access to designated psychosocial support systems to ensure that the family are adequately supported emotionally, physically, and financially from outset.

Our Asks

- The Department of Children, Equality, Disability, Integration and Youth needs to meaningfully invest in services and supports being offered to premature babies and their families.
- The Department of Children, Equality, Disability, Integration and Youth must support increased access to community-based services by introducing timelines and processes for referral to support services in the community such as those offered by the INHA.

Parental Supports Following Bereavement

Sadly, baby loss is not uncommon. The latest figures available from the National Perinatal Epidemiology Centre are from 2017 and they show that in Ireland 381 babies died. Stillbirths accounted for 235 (61.7%), early neonatal death accounted for 111 (29.1%) and late neonatal deaths accounted for 35 (9.2%). Baby deaths from multiple births accounted for 12.4% of all baby deaths (Source: <https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/NPECPerinatalMortalityinIrelandAnnualReport2017.pdf>).

For bereaved parents, it is often helpful to seek additional support outside of the support that they receive from family and friends as parental grief can bring about particular challenges. Some bereaved parents seek organised supports from baby loss organisations which may involve professional counselling but many of these organisations, operate on a voluntary basis and do not receive State funding and struggle to provide such supports.

The Government must develop and implement a policy on mental health needs for parental bereavement. This assessment needs to inform future mental health policy.

Our Asks

- Future Government policy on mental health needs a coherent plan for parental bereavement care with a review of resources required, which are benchmarked against existing best practices and standards. This plan must include an assessment of the capacity of voluntary sector to provide sufficient counselling and emotional supports to meet needs of bereaved parents in an appropriate and evidence-based way.
- Representative organisations, including the INHA, and bereaved parents must be involved in the research as key stakeholders. This should be led by the Department of Health, as part of mental health policy and strategy.

More information

If you would like any further information on our concerns and asks outlined above, please contact:

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