The importance of multi-agency planning for children with a palliative care pathway

Professionals from Birmingham Children's Hospital and Birmingham Children's Trust met to consider the learning following the death of a 3 month-old child who was born prematurely with a range of multiple health needs, meaning the child's prognosis was poor. The child's birth parents were known to agencies due to their drug misuse, which had led to a pre-birth child protection plan. The parents did not engage with a pre-birth assessment or ante-natal care, and following legal advice there was a plan to initiate care proceedings to seek an Interim Care Order following birth.

Following birth, it was clear the child required more specialist palliative care, leading to them being transferred to Birmingham Children's Hospital. Engagement with the child's birth mother became more positive which led to a decision not to pursue care proceedings, although this engagement was not sustained. This led to difficulties in terms of end of life planning as no one was effectively able to discharge parental responsibility, despite the social worker and key staff at the hospital having a good relationship with the mother. Although the child was subject to a child protection plan, there was insufficient rigour in terms of the use of existing meetings, such as core groups, to consider multi-disciplinary planning in palliative care related issues. Better multi-agency working would have enabled key professionals to agree on a plan with contingencies in place, such as arrangements for decisions required out of hours. The child sadly passed away over a weekend with neither the child's birth mother or social worker present.

Key Learning

The De-Brief Meeting between key professionals identified the following key learning:

- Decisions concerning whether to initiate care proceedings are often complex and can be emotive when a child has been born with complex health needs and a poor prognosis, and a parent shows signs of improved engagement. There needs to be a clear multi-agency view about whether this improvement is likely to be sustained taking into account what is known about the family history and risks.
- There was some level of confusion between professionals as to whether a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) had been agreed by previous health care professionals with the birth mother due to the assessment of the child's medical needs in-utero, but this did not appear to be recorded in a way that directed all professionals in their post-natal care of the child.
- The social worker was reported to have developed a good relationship with the birth mother, despite the challenges of engaging her in the work outlined within the Safety Plan. This highlights the importance of adopting a 'relationship and restorative' based approach with parents, which builds on their strengths and where practice is trauma informed
- The importance of using multi-agency meetings, such as core groups or palliative care planning, to agree an end of life plan, to include key roles and responsibilities for engaging with birth parents when there are 'reachable moments', to have difficult conversations, and how to ensure that a child has a dignified death with the right people present.
- Professionals working together to form a clear assessment and professional view of parental capacity when a parent's drug misuse means that they are unable to make informed decisions with regards to palliative care.
- There could have been inclusion within the outline child protection plan from Child Protection Conferences of the specific need for professionals to have multi-agency meetings to plan for palliative care or for discharge.

Improving Practice

- If you are working with a child who has complex health needs, is on a palliative care pathway, and open to Birmingham Children's Trust, work collectively through a multi-agency meeting to agree a plan with contingencies, clear roles, and responsibilities. This can be done via the Child in Need meeting, Core Group, Care Planning meeting or, more specifically, using multi-agency Palliative Care or Discharge Planning meetings. Ensure that the plan also considers what happens 'out of hours' when key professionals like the social worker may not be available.
- Make sure you are clear when a professional tells you about a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) agreement that you are clear what this refers to in terms of what happens and in what circumstances – seek written evidence of this if possible.
- Make sure you are also thinking about your own welfare and whether as a practitioner you need to access some support when a child you are working with sadly passes away.

Next Steps

- Circulate this Learning Lessons Briefing Note to all members of your team.
- Familiarise yourself with West Midlands Safeguarding Children Procedures 'Children living away from home including in hospitals' - 2.16 Children living away from home | West Midlands Safeguarding Children Group
- Discuss within individual or peer supervision, a team meeting, or a practice forum to ensure that practitioners can reflect on the lessons from this briefing note and consider how they can apply them to their own practice.
- Visit the BSCP multi-agency training webpage for more information on relevant safeguarding training.