

Coalition Bereavement Group Report -- November 11, 2016

The group considered the tasks of identifying needs across the state, cataloging and assessing resources available, and developing strategies to support and assist families bereaved by the death of a child.

In view of the scattered resources available and differences of effectiveness and quality, it was agreed that assessing and cataloging these has to be a long term goal. For the time being the group will focus on identifying needs and developing strategies of support.

Factors of need:

- *Economic*: Economic impact is usually short term resulting either from reduced work capability while caring for a child in fragile health before death, or reduced productivity through grief immediately after death or both.
- *Time*: The grief of a parent for the loss of a child has no boundary of time. This is the most disturbing and enduringly painful form of bereavement. Means of support need, accordingly, to be available to parents who have lost a child recently and many years ago.
- *Suicidal ideation*: Thoughts of suicide are common among those who have lost a child and are usually no more than an indicator of the seriousness of the loss.

Strategies for Support:

- Ensuring that the death of a child is without fear of pain is imperative. A 'good death', or at least the best that can be realistically expected, can lessen the severity of grief.
- The relationship between the family and the medical professionals who cared for the child should not end at death. Before death, the family's dependence on the caregiver has been total. A lot of research now suggests that many families benefit from candid discussions with medical staff before the death and a follow-up conversation in the weeks after. Following the death, the caregiver should also, if at all possible, help the family transition to other supports.
- Support needs to be multi-faceted and involve the health professional, therapists trained in grief support, other families who have suffered grief through peer support, the employer and the community. For the community there is a need for education on parental bereavement.
- Providing opportunities for a parent to tell his or her child's story. Parents can derive comfort from finding ways of memorializing a child and formulating new rituals of remembering.

Action:

- *Peer-to-peer support*: Making use of existing resources, parent members of the Coalition, and the help of hospitals, hospices and government offices like the Department of Health, the Bereavement group can help advance and facilitate support of families by families.
- *Opportunities to tell the child's story*: The Bereavement group can encourage families to tell their stories and provide outlets for communicating with broader audiences. Already an effort has been started to tell children's stories through pictures. The pictures could be by the deceased child or by a sibling or other family member. If enough stories and pictures can be gathered, the group can contemplate appropriate exhibitions or a publication. The objective is not only to provide a narrative outlet for the parents but also help to educate communities.
- *Website*: The Coalition website can include a memorial page, illustrating the fact that children die and that there is need for the services of the Coalition.