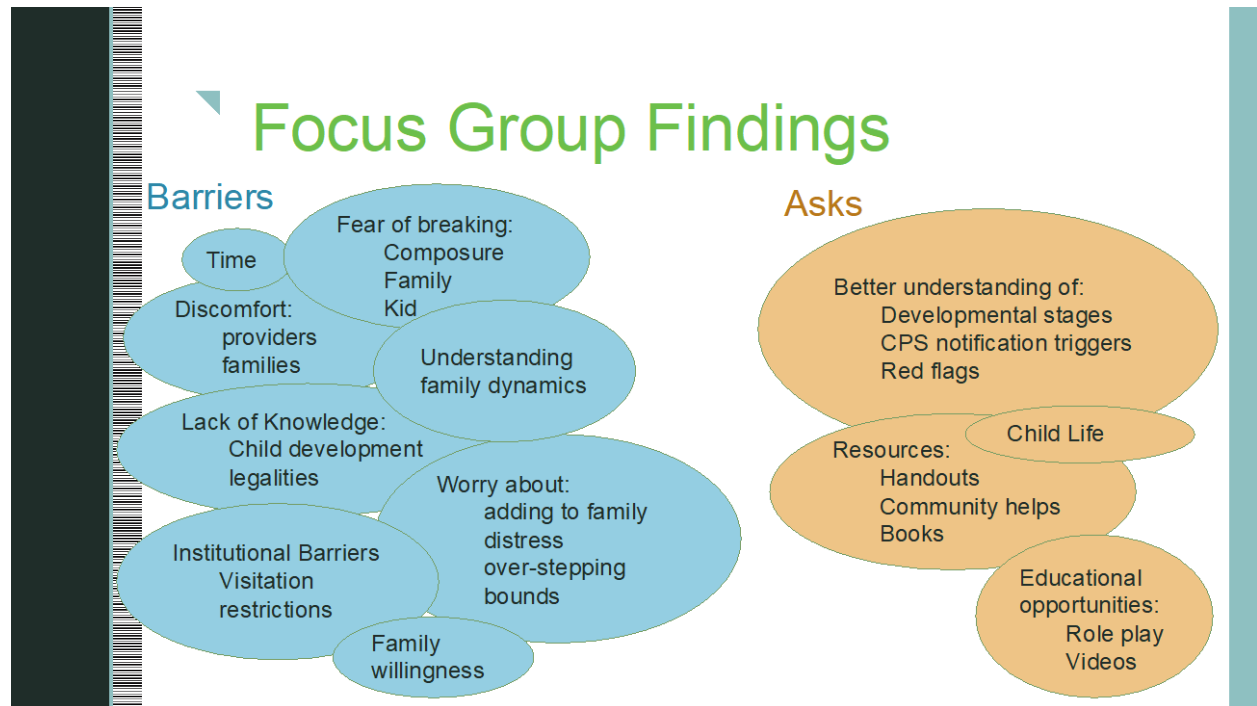
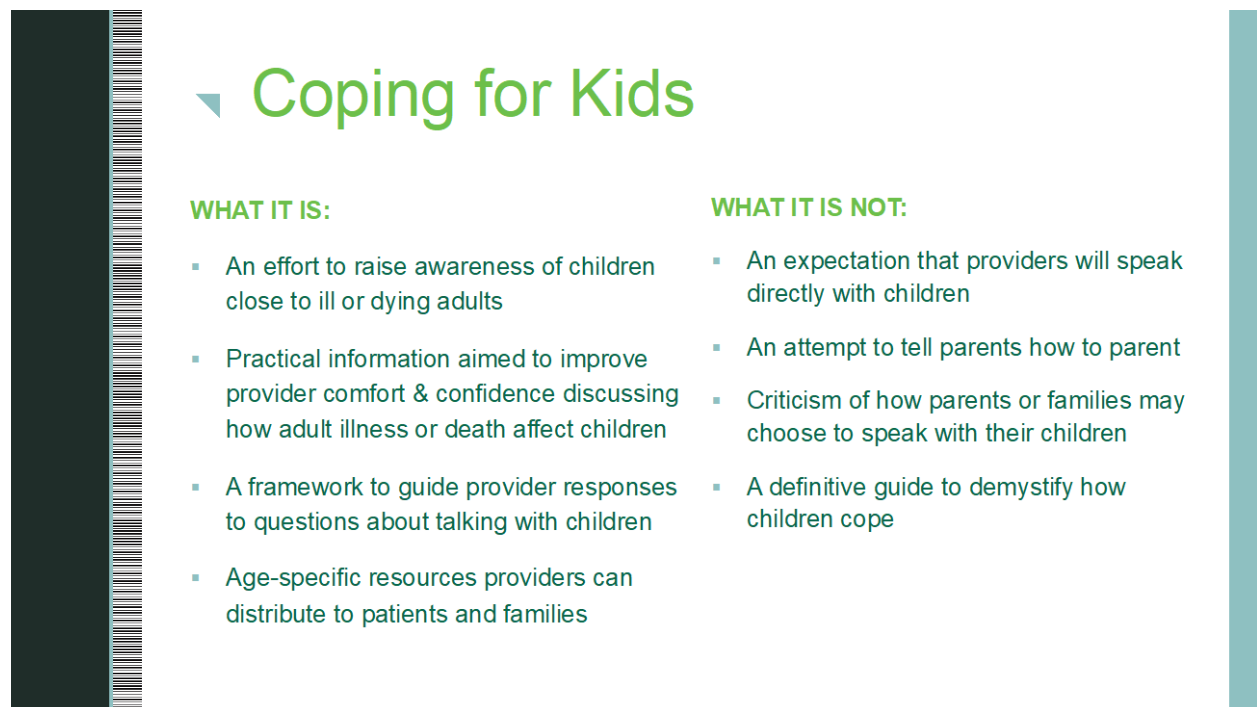


Focus Group Findings



Program Development – Resource packets, Provider tip sheet



◀ Coping for Kids

Information for patients and families

Coping with Grief in Infants or Toddlers

Babies have no concept of death, therefore it has very little meaning. They do not understand the meaning of "alive" and "dead" or know that death is permanent. Your presence and loving hugs will be important to your child as they adjust to this loss. Always remember, it is important for kids to play and get lots of hugs.

Feelings:

Babies can sense emotions from caregivers who are sad, angry, or frustrated. They also respond to the grief of the adults taking care of them. They will sense sadness, worry, and absence of a loved one. They will feel and know that something is very wrong.

Since babies cannot tell you their needs when your baby is grieving, it is normal to have:

Physical feelings:

- increased crying
- sucking
- biting

Behavioral changes in:

- sleeping
- more irritable
- less appetite
- mood
- eating
- increased clinging

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Grief & Serious Illness

- General Handout
- Infants
- Preschoolers
- School Age
- Older School Age
- Teens

◀ The Provider Tip Sheet

Authors: Bennett, K; Horowitz J; Nielsen, E

Version 1

Date: 3-5-2019

Provider Tip Sheet: Supporting Family Discussions Involving Minor Children Affected by a Loved Adult's Chronic Illness and Approaching Death

Identifying Patients and Families for Whom Additional Resources May Be Beneficial

Goals: (1) Determine whether minor children are affected; (2) Understand the family's progress to date discussing the adult's illness with the children; (3) Explore collateral supports, patient, and family

Considerations:

1. Identify all children who may be affected, including their ages, relationship, and loved adult.

Assessment Prompts

- Identify affected children
- Understand family dynamics
- Clarify collateral supports
- Explore comfort with communication

Frequently Asked Questions and Tips for Answering Them

1. How does age affect children's understanding of illness and death?

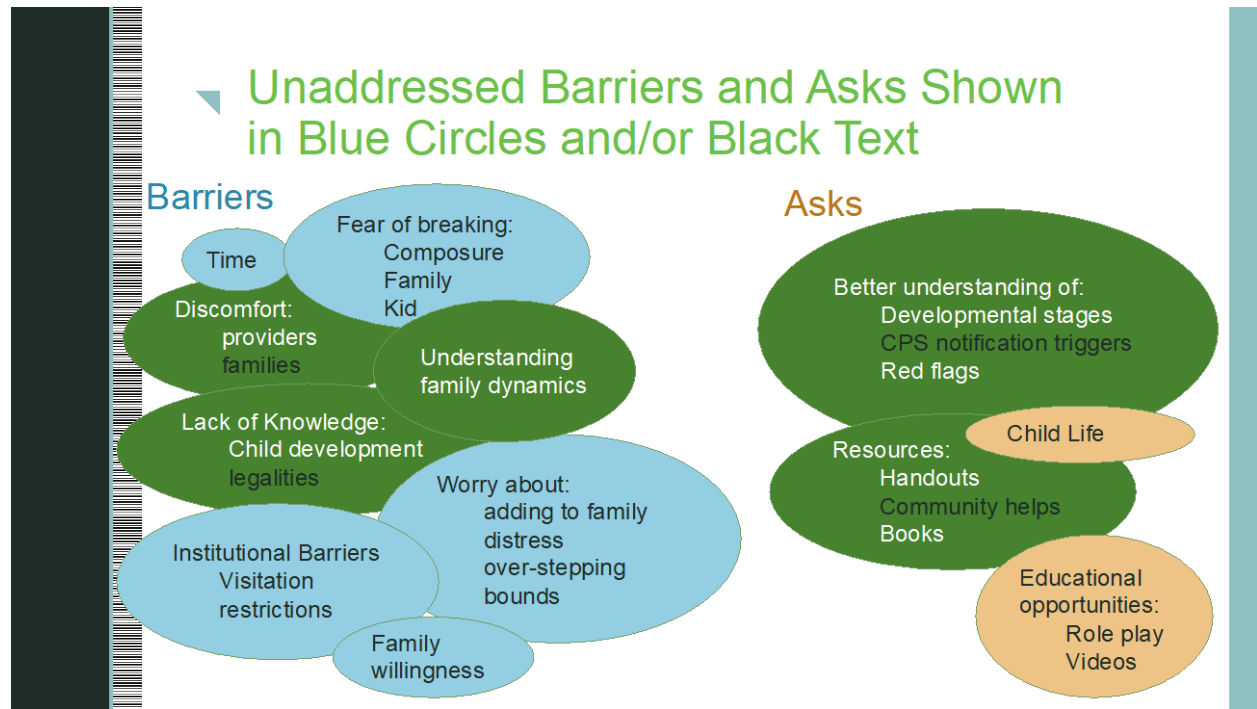
- Infant/Toddler:** Limited understanding. Consistency, routine and a small, reliable group of caregivers are important.
- Preschool:** Magical thinking (I cause things; all things happen because of me or something to do with me). Often "act out" or regress to indicate distress. Reassure them nothing they did/didn't do caused the illness and they cannot catch the illness.
- School-aged:** Fairness is important. Acknowledge unfairness, disappointments, frustrations, lack of control associated with the illness. Emphasize that they did/didn't do caused the illness. The ill patient is no longer able to fulfill their role. Child to see where treatments work.
- Teens:** Expect anything. Common to feel angry, sad, and more limited. Encourage them to talk to friends, peers, and family.

Educational Reminders

- Developmental changes
- What may be said
- Communication with schools
- Coping & red flags

Published books that address grief and coping and target toddlers, early elementary, pre-teens and teen children also made available for distribution to families (grant supported portion of program)

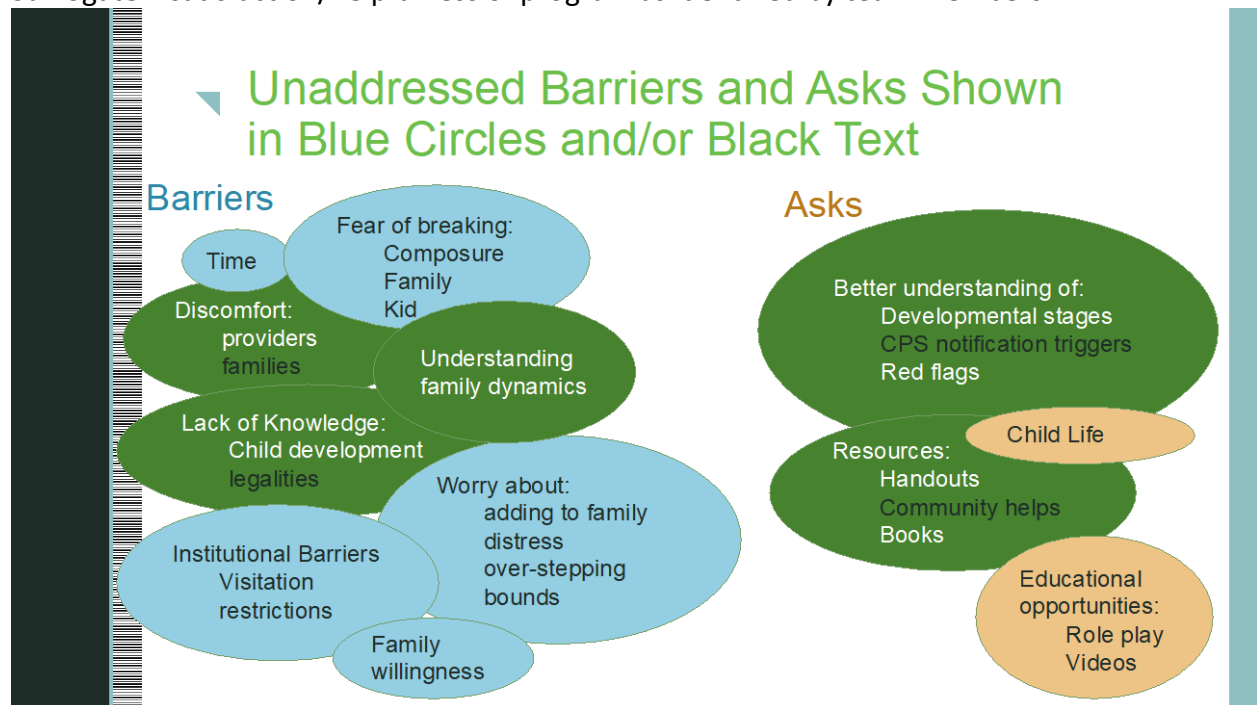
Remaining Barriers



Balancing Measures

Time / Work Load – difficult to track

Surrogate = satisfaction/helpfulness of program as identified by team members



Future Directions

Ongoing tracking of resources, expansion to chaplains, outpatient clinic

Attempt to quantify affected children

Family satisfaction measure