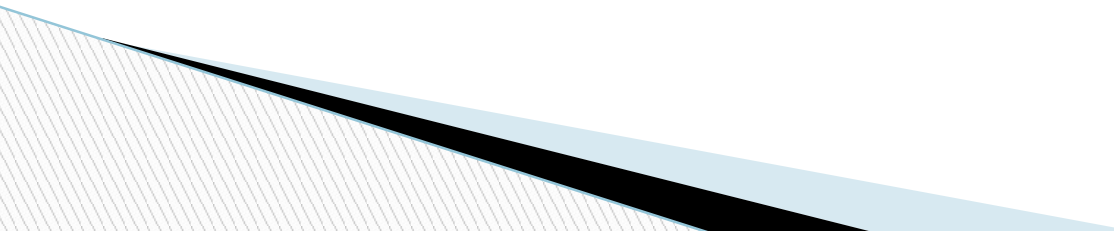


Supports for Families in Neonatal Intensive Care Units in Jamaican Hospitals

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Supports for Families in Neonatal Intensive Care Units in Jamaican Hospitals

- ▶ Conflict
 - ▶ Confessions
 - ▶ (Thanks Prof. Emond)
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Presentation Outline

- ▶ Background
- ▶ Aims & Objectives
- ▶ Method
- ▶ Results
- ▶ Discussion & Recommendations
- ▶ Next Steps

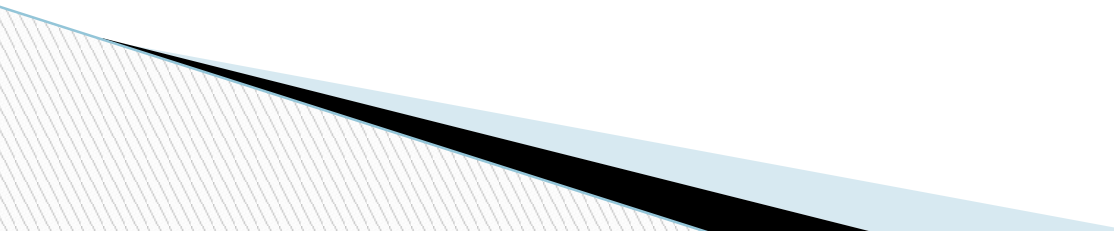


Supports for NICU Families

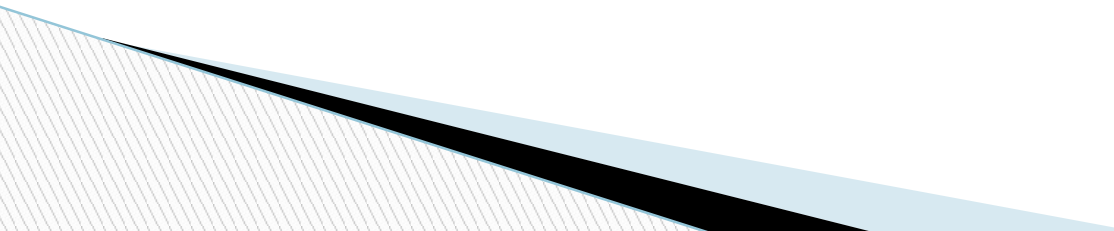
Background



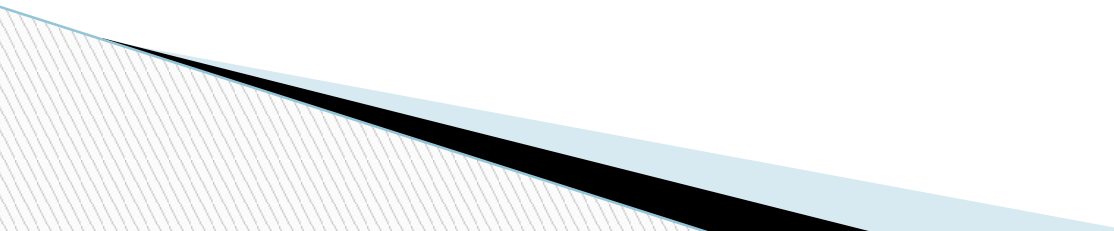
What is a NICU?

- ▶ A NICU, sometimes called a special care nursery, cares for babies who are born early, who have problems during delivery, or who develop problems and require a higher level of care.
 - ▶ Although all NICUs care for babies who need extra help, different NICUs offer different levels of care.
- 

The neonatal environment

- ▶ Newborns are placed in the neonatal care sections of hospitals for a variety of reasons including prematurity, sepsis, and respiratory difficulty.
 - ▶ The neonatal environment can be a stressful and frequently frightening experience for parents.
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The neonatal environment

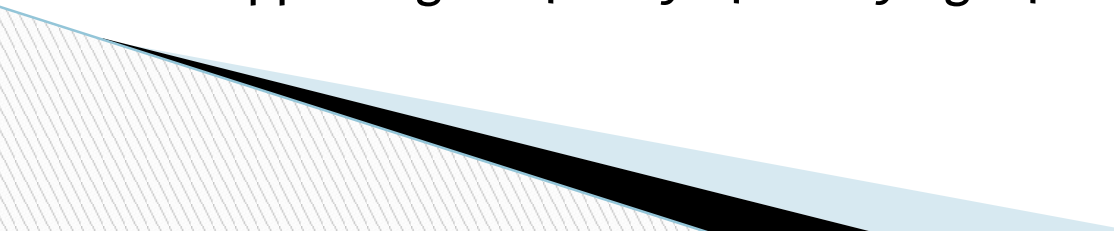
- ▶ Parents whose babies are admitted to a neonatal unit are often:
 1. facing difficult situations which contrast with conventional postnatal care and transition to parenthood (POPPY Steering Group, 2009).
 2. experiencing stress, uncertainty and are concerned about longer term outcomes for their baby.
 3. encountering challenges to the development of their parenting roles (Heerman, Wilson, & Wilhelm, 2005).
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What is family support?

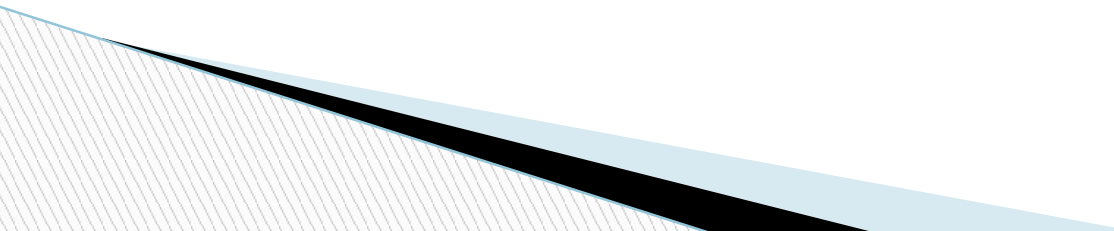
- ▶ Enabling parents to care for, take responsibility for, and gain knowledge about their sick and preterm infant is the very essence of family support.



Types of Family Support

- ▶ Supporting the family in the antenatal period
 - ▶ Supporting the family during the admission period
 - Clear, concise, written information
 - Social Work – transportation support
 - ▶ Being aware of the profound effects of separation
 - Dedicated Phone lines
 - Parent rooms
 - ▶ Supporting the family during the discharge preparation period
 - Transition-to-Home Support
 - Discharge planning starts at admission
 - ▶ Supporting the family of the dying infant
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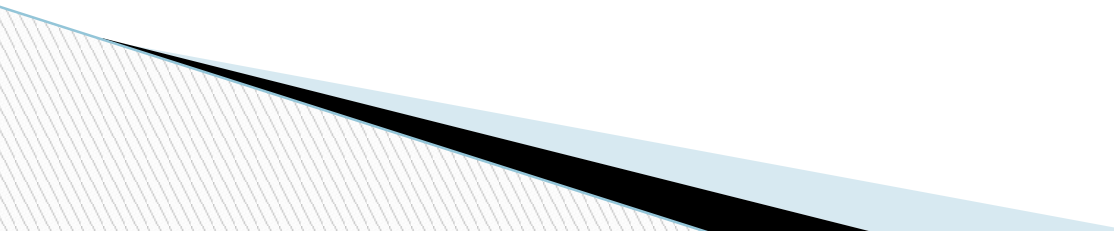
Considerations in a Family Centered Approach

- ▶ Active vs. passive
 - Family centred care emphasises a shift from the family as passive recipient to the family as active participant in their infant's care.
 - ▶ Parents are not a homogenous group. Nurses need to look closely at the cultural and social backgrounds of the parents to provide adequate support for the whole family
 - ▶ Family support must encompass the whole family, including siblings
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The Jamaican Context

- ▶ NICUs
 - Bustamante Hospital
 - Cornwall Regional
 - UHWI
 - Mandeville

 - ▶ Type B's and even some Type C's

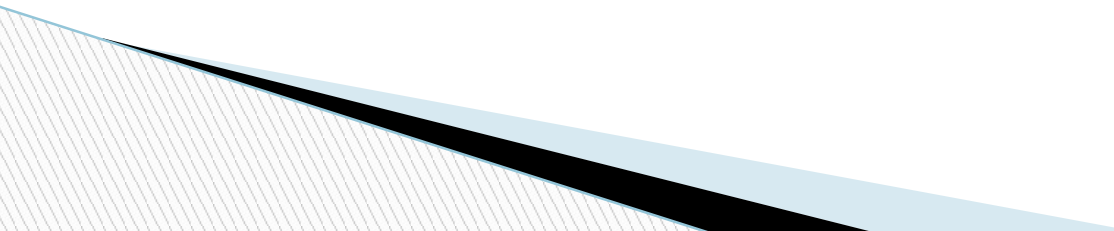
 - ▶ Parent Support
 - Training Manuals
 - There is a start but we can do more
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Aims & Objectives

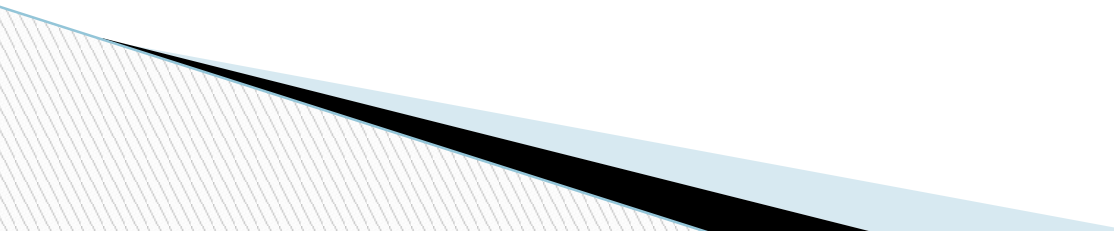
» Supports for NICU Families



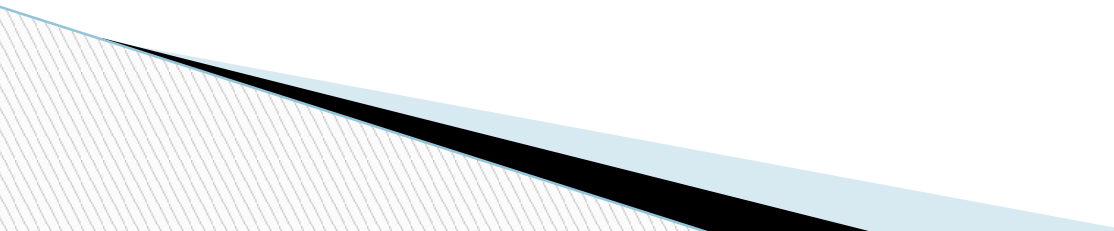
Aim of Research

- ▶ This study intends to address the absence of research on Parent Support in the Jamaican context by examining the extent of parenting supports available in the neonatal facilities in Jamaica, and the effectiveness of such supports.
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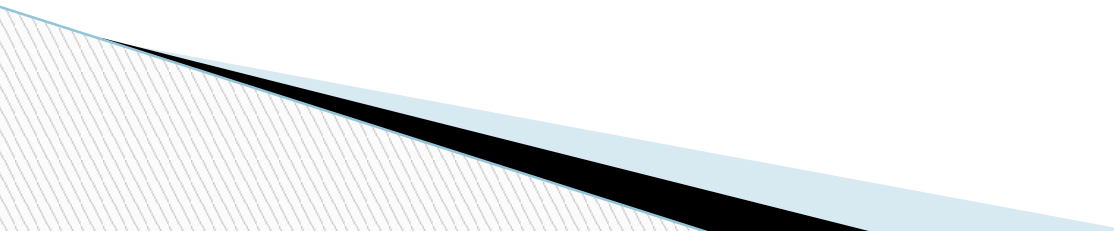
Objectives

1. Identify the needs of parents who have infants in Jamaican neonatal units
 2. Identify the services and facilities that are provided for parents in Jamaican neonatal units
 3. Determine if there are any national or hospital-specific policies in place (formal or informal) which aim to support parents of newborns and address their needs
 4. Document gaps if any in facilities and services that should/could be addressed to enable parents to experience needed supports at these critical times.
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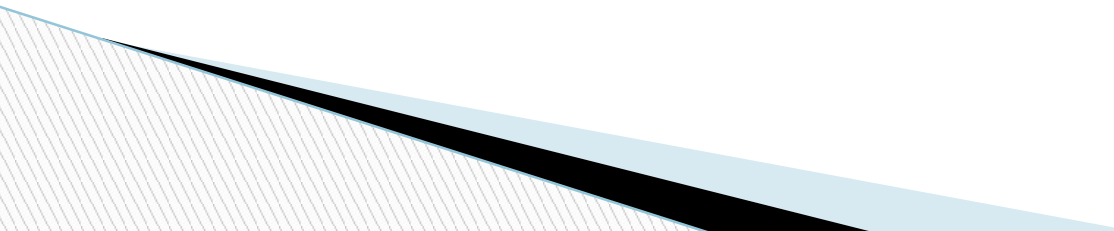
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Research Questions

- ▶ What are the needs of parents who have infants in Jamaican neonatal units?
 - ▶ What supports/policies currently exist for parents with an infant in Jamaican neonatal units?
 - ▶ What kinds of supports do parents of neonates say was helpful or needed at this time?
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Research Questions

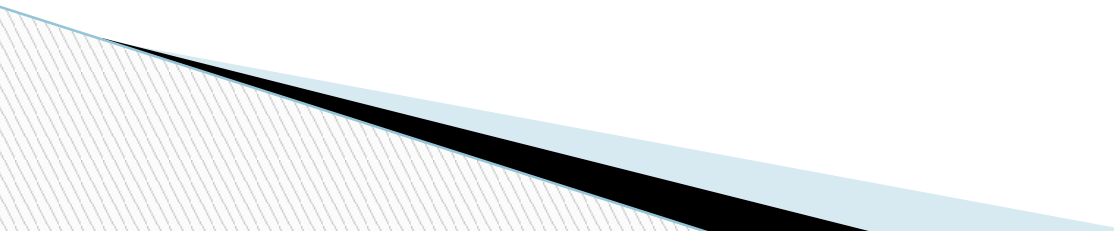
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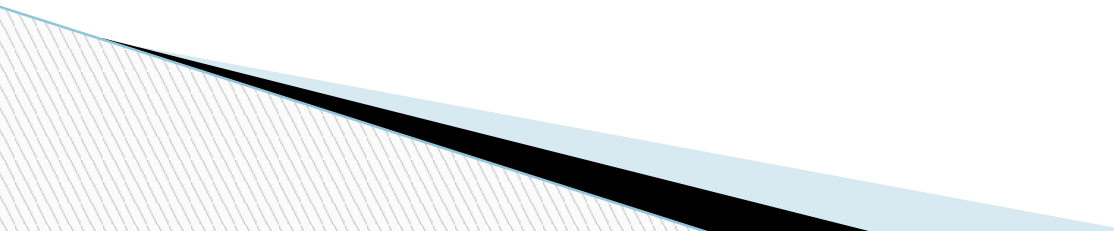
Supports for NICU Families

METHOD

Method – Participants

- ▶ The Parent Support study made use of data from the JA KIDS birth cohort study.
 - ▶ The **JA KIDS cohort** is comprised of all children born in Jamaica All in July, August & September 2011 (N=11,124 births).
 - ▶ To date, 9700 families have been enrolled in **the JA KIDS study**.
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Method – Procedure

- ▶ During the 9 – 12 month telephone follow-up contact with participants, primary caregivers were asked questions about their health and well-being, their child's growth and development, the child's environment, nutrition and parental practices .
 - ▶ An additional set of questions were asked of primary caregivers whose child/children had been admitted to the hospital in order to capture their opinions of the support they received from the staff while their child was hospitalized.
- 

Method – The Parent Support Questionnaire

- ▶ Level of satisfaction with how family was treated:
 - **While your child was in the NICU/Nursery, how satisfied were you with:**
 - *How the doctors treated your child?*
 - *How the nurses treated your child?*
 - *How the staff cared for/about you, apart from your child?*

Method – The Parent Support Questionnaire

- Level of satisfaction with amount of information that hospital staff (doctors & nurses) gave parents about their child's illness:
 - *Did you think that the information given to you about your **child's illness** was easy to understand?*
 - *Was the information about your **child's illness** given to you in a timely fashion? (i.e. when you needed it most)?*
 - *Did you want information on your **child's illness***

Method – The Parent Support Questionnaire

- ▶ Level of satisfaction with the amount of information that they (doctors and nurses) gave you about the **treatment of your child's illness** (e.g. medications, tests)?
 - *Did you think that the information given to you about the **treatment of your child's illness** was easy to understand?*
 - *Was the information about **the treatment of your child's illness** given to you in a timely fashion? (i.e. when you needed it most)?*
 - *Did you want information on the **treatment of your child's illness**?*

Method – The Parent Support Questionnaire

- ▶ Level of satisfaction with the amount of information that hospital staff (doctors and nurses) gave parents about the **daily care of child** (e.g. feeding, bathing, changing diapers etc)?
 - *Did you think that the information given to you about the **daily care of your child** was easy to understand?*
 - *Were you satisfied with the amount of information you received about the **daily care of your child**?*
 - *Was the information about the **daily care of your child** given to you in a timely fashion? (i.e. when you needed it most)?*
 - *Did you want information on the **daily care of your child**?*

Method – The Parent Support Questionnaire

▶ Level of Parent Support:

- *While your child was in hospital, did anyone tell you about any other services or persons **WITHIN THE HOSPITAL** to help you understand or cope with your child's situation?*
 - *If yes, name service and say if it was helpful*
 - *If no, would you have wanted this?*
- *While your child was in hospital, did anyone tell you about any services or persons **OUTSIDE THE HOSPITAL** to assist you and/or your child?*
 - *If yes, name service and say if it was helpful*
 - *If no, would you have wanted this?*

Method – The Parent Support Questionnaire

- ▶ Level of Parent Support (cont/d):
 - *Is there anything/anyone that was particularly helpful to you while your baby was in the hospital? e.g. one special staff member, informal or formal parent group, counseling, written materials, orientation to the NICU (rules, dress code, etc.)*
 - *Is there anything that **you wish you had been offered** that would have been helpful?*

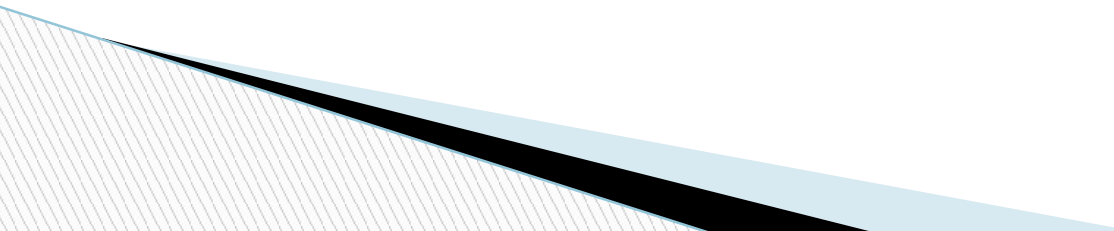
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Results



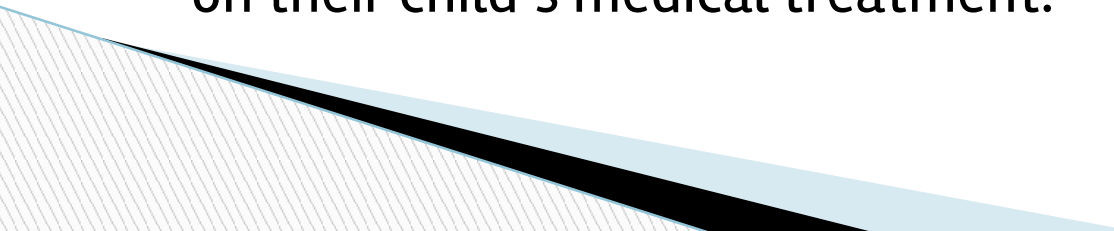
The Sample

- ▶ There were 427 families participating in this sub-study on parenting supports in the health sector.
 - ▶ The mean age of mothers participating in the study was 26 years (range 13 years – 46 years)
 - ▶ The mean age of fathers participating in the study was 33 years (range 17 years – 57 years).
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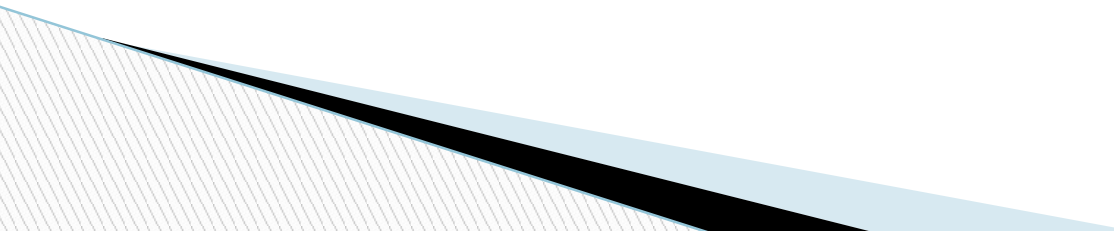
Satisfaction with Treatment by Staff – Information on Illness

- ▶ Forty-eight percent of parents were “very satisfied” with the information they received about their child’s illness.
- ▶ The majority of participants thought that this information was “easy to understand” (79%) and given in a “timely fashion” (72%).
- ▶ Almost all parents (93%) wanted information about their child’s illness.

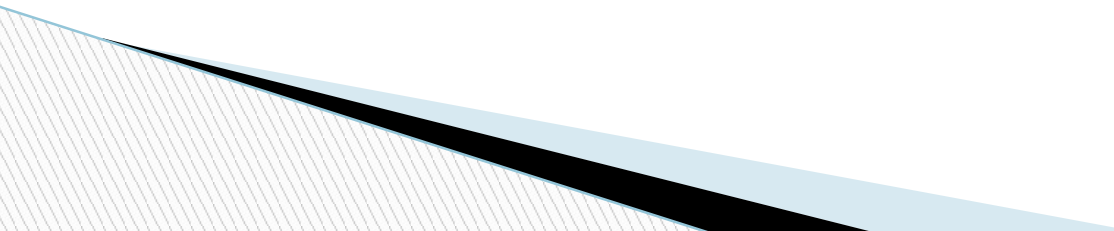
Satisfaction with Treatment by Staff – Information on Treatment

- ▶ Forty-five percent of parents reported being “very satisfied” with the amount of information that they received about the medical treatment (medication, tests) of their child.
 - ▶ Seventy-seven percent of the sample said that this information was “easy to understand”.
 - ▶ However, only 10% said that they received this information in a timely fashion.
 - ▶ Eight-nine percent of parents said that they wanted information on their child’s medical treatment.
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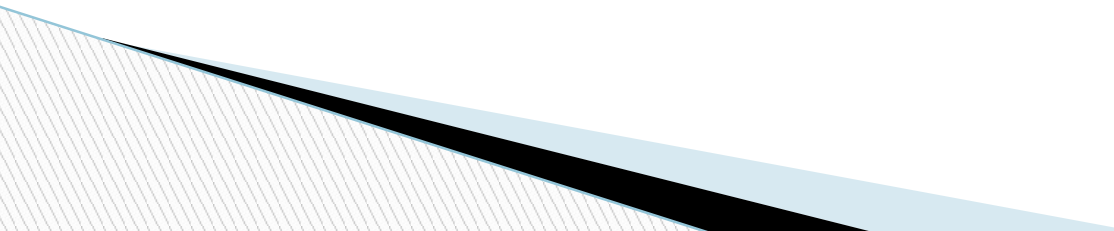
Satisfaction with Treatment by Staff – Information on Daily Care

- ▶ Forty-three percent of parents reported being “very satisfied” with the amount of information that they received about the daily care (feeding, bathing, changing diapers etc) of their child while in the hospital.
 - ▶ Seventy-eight percent of the sample said that this information was “easy to understand”
 - ▶ 85% said that they wanted information on this.
- 

Parenting Supports

- ▶ Only 19% of parents reported that they were told about services within the hospital that could help them understand or cope with their child being admitted to hospital.
 - ▶ All parents who received this information said that it was helpful.
 - ▶ Conversely 48% of those parents who did not receive this information reported that they would have wanted information on services.
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Parenting Supports

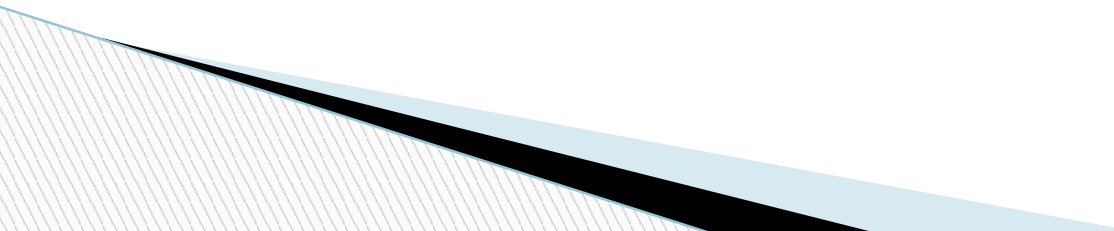
- ▶ Twelve percent of parents reported getting information on the services that were available outside of the hospital that could help them understand/cope with their child's illness.
 - ▶ However, 40% of parents who did not receive this information reported that they would have wanted to be referred to these services.
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Supports for NICU
Families

Discussion & Recommendations

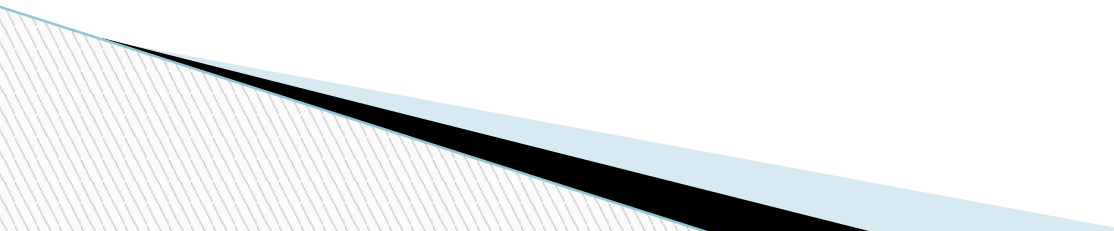
Summing Up!

- ▶ Parents want information!
 - ▶ Parents got some information about their child's illness, treatment and daily care and the majority felt that this information was relatively to understand.
 - ▶ This information was not given in a timely fashion especially as it relates to treatment
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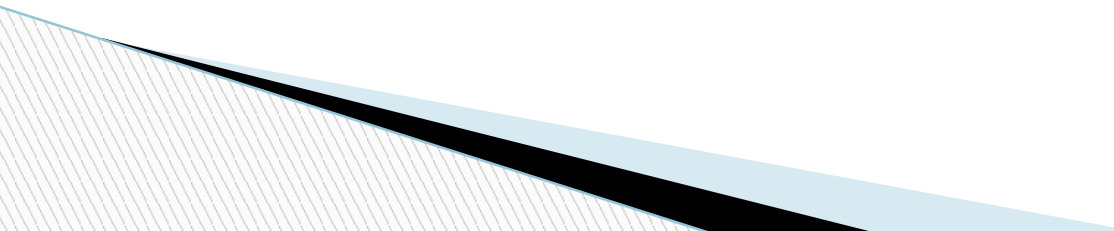
Summing Up!

- ▶ Parents are not getting information about services/supports within OR outside of the hospital
- ▶ Is it a case that there are NO services?
 - Social Worker
 - Directory of organizations

How can we increase supports for NICU families?

- ▶ Mechanisms for Family Support:
 - NICU Staff
 - NICU Design and Supportive Services
 - Parent Support Groups & Parent-to-Parent Support
 - Online and Technology-Based Support
- 

Next Steps

- ▶ Review of policies/programmes related to parent support
 - ▶ Engaging groups, e.g. National Parenting Support Commission
 - ▶ A survey of neonatal units in Jamaica will help to develop our understanding of what units do and what facilities they provide to support parents and provide family-centred care.
 - ▶ Focus groups with parents whose children were admitted to a NICU/nursery will provide more detailed information on parents' experiences of having a child in the NICU/nursery and their perceptions of the acceptability and appropriateness of the support services, facilities and information they were offered, or saw being offered in these units.
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Acknowledgements

▶ Special Thanks to:

- All the families who participated in this JA KIDS sub-study
 - The JA KIDS telephone interviewers for collecting this data at the 9 – 12 month contact
 - Parenting Partners Caribbean for providing funding for two data entry staff – Simone Burke and Tara Wright – to assist with collecting and entering this data during July and August 2012.
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