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Supplemental Digital Content 2

Family-Centered Care Hospital Policies and Practices Scale – Hospitals Caring for Pediatric Patients

This 44-item survey assesses the perceptions of hospital leaders, healthcare professionals, and family support service providers of the family-centeredness of policies and practices. The total and subscale scores can be used to help determine initial priorities and action steps for family-centered care awareness, education, and improvement. It can also be used to track progress over time.

Instructions: Please rate each item according to how it best represents the policies and practices at your children’s hospital, pediatric service or in your neonatal or pediatric unit or department.

| Family-Centered Care (FCC) Items | Ratings | | | | | |
|---|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|-----------------------|
| FCC Culture and Policies (6 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
| 1. Family-centered care is integrated as a core value and priority | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Our mission, vision, values, and/or philosophy of care statements convey a commitment to family-centered care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Written policies refer to families as essential members of the health care team and not as "visitors" | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. We welcome families 24 hours a day, 7 days a week | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Written policies and staff practices make a distinction between families and visitors (i.e., friends, relatives who may wish to visit) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. We have protocols for supporting safe sibling presence | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Participation in Care and Decision-Making – Part 1 (10 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
| 7. We encourage families to identify how they want to be involved in: Direct care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. We encourage families to identify how they want to be involved in: Care planning and decision-making | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| Family-Centered Care (FCC) Items | Ratings | | | | | |
|---|--------------------------|-----------------------|-----------------------------------|-----------------------|-----------------------|-----------------------|
| 9. Care planning and decision-making incorporates the cultural and spiritual beliefs and practices of families | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Physician and nurse practices support family participation in: Direct patient care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Physician and nurse practices support family participation in: Care planning | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Physician and nurse practices build on the confidence and competence of families to support family participation in: Decision-making | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. Physician and nurse practices support family participation in: Daily medical rounds | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Physician and nurse practices support family participation in: Planning transitions and discharge | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Physician and nurse practices support family participation in: Planning end-of-life care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Physician and nurse practices encourage and support children and adolescents in planning their care, as developmentally appropriate | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Participation in Care and Decision-Making – Part 2 (2 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
| 17. Physician and nurse practices support family participation in: Nurse change of shift | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. Physician and nurse practices support families to be present during codes or other emergency situations | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Information Sharing (5 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
| 19. Families are welcomed as essential members of the health care team in pre-admission materials, family welcome packs and handbooks | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. Families are welcomed as essential members of the health care team on our hospital website | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 21. We welcome and support families through signage that is prominent and worded positively | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 22. We provide informational materials that are understandable and appropriate for families we serve (e.g., languages, reading levels, formats) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| Family-Centered Care (FCC) Items | Ratings | | | | | |
|----------------------------------|---------|--|--|--|--|--|
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|---|---|---|---|---|---|---|
| 23. We provide interpreters when needed | ○ | ○ | ○ | ○ | ○ | ○ |
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| Family-Centered Care (FCC) Items | Ratings | | | | | |
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| Support for Families (5 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
|--------------------------------|-------------------|----------|----------------------------|-------|----------------|--------|
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| 24. We ensure that staff ask families about basic needs that may affect their health (e.g., housing, food insecurity) | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|

| | | | | | | |
|--|---|---|---|---|---|---|
| 25. We ensure that staff connect families to appropriate community resources, as needed (e.g., social services, parent support associations) | ○ | ○ | ○ | ○ | ○ | ○ |
|--|---|---|---|---|---|---|

| | | | | | | |
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| 26. Adequate and comfortable space and furniture (chair and/or bed) provided at the patient’s bedside | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|

| | | | | | | |
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| 27. We provide peer support programs for families | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|

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| 28. We offer financial support to families for parking, meals, overnight accommodation and childcare, as needed | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|

| Staff Education and Performance (6 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
|---|-------------------|----------|----------------------------|-------|----------------|--------|
|---|-------------------|----------|----------------------------|-------|----------------|--------|

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| 29. We describe the necessity of partnering with families as members of the health care team in: Orientation for physicians | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|

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| 30. We describe the necessity of partnering with families as members of the health care team in: Orientation for nurses and other clinical staff | ○ | ○ | ○ | ○ | ○ | ○ |
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| 31. We describe the necessity of partnering with families as members of the health care team in: Inservice and continuing education for physicians | ○ | ○ | ○ | ○ | ○ | ○ |
|--|---|---|---|---|---|---|

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|---|---|---|---|---|---|---|
| 32. We describe the necessity of partnering with families as members of the health care team in: Inservice and continuing education for nurses and other clinical staff | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|

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|---|---|---|---|---|---|---|
| 33. We clearly describe the necessity of partnering with families as members of the health care team in position descriptions | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|

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| 34. We clearly describe the necessity of partnering with families as members of the health care team in performance appraisals | ○ | ○ | ○ | ○ | ○ | ○ |
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| Family-Centered Care (FCC) Items | Ratings | | | | | |
|---|-------------------|----------|----------------------------|-------|----------------|--------|
| Cultural Sensitivity Education (3 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
| 35. We provide orientation and education programs to prepare physicians for culturally sensitive practice | 0 | 0 | 0 | 0 | 0 | 0 |
| 36. We provide orientation and education programs to prepare nurses and other clinical staff for culturally sensitive practice | 0 | 0 | 0 | 0 | 0 | 0 |
| 37. We provide orientation and education programs to prepare hospital leaders for culturally sensitive practice | 0 | 0 | 0 | 0 | 0 | 0 |
| Family Participation in Healthcare Improvement (7 items) | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
| 38. We collect information about the family experience of care through surveys or post-discharge phone calls | 0 | 0 | 0 | 0 | 0 | 0 |
| 39. We collaborate with families to improve the experience of care, quality, equity, and/or safety through a family advisory council or family participation on hospital committees | 0 | 0 | 0 | 0 | 0 | 0 |
| 40. Family advisors reflect the race, ethnicity, linguistic, gender, sexual orientation, and socio-economic diversity of communities served by the hospital | 0 | 0 | 0 | 0 | 0 | 0 |
| 41. We communicate the efforts and impact of family advisors to hospital leaders | 0 | 0 | 0 | 0 | 0 | 0 |
| 42. Our hospital leaders, through their words and actions, hold all staff accountable for family-centered care | 0 | 0 | 0 | 0 | 0 | 0 |
| 43. Our hospital leaders provide rewards and recognition for family-centered practice by hospital staff | 0 | 0 | 0 | 0 | 0 | 0 |
| 44. Our hospital leaders invest time and financial and personnel resources in family-centered care initiatives | 0 | 0 | 0 | 0 | 0 | 0 |
| Total score (sum scores 1=strongly disagree to 5=strongly agree; point range: 41-205); 8 sub-scales | | | | | | |

| Partnership with Family Support Organization Items | Ratings | | | | | |
|--|---------|--|--|--|--|--|
|--|---------|--|--|--|--|--|

45. Does your hospital have a partnership with any community-based organization that provides family housing and support services (e.g., Ronald McDonald House, etc.)? Yes No Unsure

If no, skip to next section.
 If yes, please complete the following items:

| 46. Having a partnership with an organization that provides family housing and support services helps our children's hospital or my neonatal or pediatric unit/department in the following ways... | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Unsure |
|--|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|-----------------------|
| 46.1. Enhances our ability to provide family-centered care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.2. Reduces costs to families | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.3. Increases parent/caregiver understanding of child's care plan | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.4. Reduces the length of time a child stays in the hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.5. Improves parent/caregiver satisfaction with hospital care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.6. Reduces the burden on our hospital in assisting families with lodging | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.7. Reduces the burden on our hospital in assisting families with food | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.8. Reduces the burden on our social work department in connecting families to community resources | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.9. Enhances the quality of care our hospital provides | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.10. Reduces costs to our hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.11. Increases the number of patients the hospital serves | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 46.12. Enhances our hospital's reputation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| Hospital and Leader Demographics Items | Ratings |
|---|--|
| 47. How many <u>neonatal/pediatric</u> inpatient beds does your hospital have? (check one) | <input type="radio"/> Less than 100 beds <input type="radio"/> 100 beds or more |
| 48. How is medical care paid for at your hospital? (check one) | <input type="radio"/> Most care is paid for by public funds <input type="radio"/> Most care is paid for by health insurance or by the family <input type="radio"/> A mix of public funds, health insurance and family |
| 49. Is your hospital affiliated with a medical school and/or university? | <input type="radio"/> Yes <input type="radio"/> No |
| 50. Is your hospital a referral center for pediatric specialty care for your region or country? | <input type="radio"/> Yes <input type="radio"/> No |
| 51. Does your hospital have an active family advisory council that meets at least 6 times a year? | <input type="radio"/> Yes <input type="radio"/> No |
| 52. In what role do you spend most of your time? (check the <u>one</u> that best fits) | <input type="radio"/> Hospital leader (non-clinical) <input type="radio"/> Hospital medical leader <input type="radio"/> Hospital nursing leader <input type="radio"/> Hospital family services leader <input type="radio"/> Unit/department leader (non-clinical) <input type="radio"/> Unit/department medical leader <input type="radio"/> Unit/department nursing leader <input type="radio"/> Physician, patient care <input type="radio"/> Nurse, patient care <input type="radio"/> Therapist, social worker <input type="radio"/> Other clinical role <input type="radio"/> Other non-clinical role |
| 53. How long have you been working in your profession? | <input type="radio"/> Less than 5 years <input type="radio"/> 5-9 years <input type="radio"/> 10-14 years <input type="radio"/> 15-20 years <input type="radio"/> More than 20 years |

Please add below any comments about family-centered care at your hospital or neonatal or pediatric unit/department:
